


Standing Committee for the Social Sciences (SCSS)

Developing a New Understanding of Enabling Health and Wellbeing in Europe

Harmonising Health and Social Care Delivery
and Informatics Support to Ensure Holistic Care

Science Position Paper



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Authors:

The content of this paper was drafted by Professor Michael Rigby, with support from Professor Sabine Koch, Dr Debbie Keeling and Penny Hill, and contributions from Dr Albert Alonso and Dr Els Maeckelberghe.

This Science Position Paper has been prepared under the responsibility of the Standing Committee for the Social Sciences (SCSS):

Chair: Professor Sir Roderick Floud

Head of Humanities and Social Sciences Unit:
Dr Nina Kancewicz-Hoffman

Editorial support:

Mr Étienne Franchineau, Junior Science Officer

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Foreword



Health is defined by the World Health Organisation as “a state of physical, mental, and social wellbeing, and not merely the absence of disease”¹. A number of different functions quite separate from clinical health services are indeed essential to maintaining health (e.g. provision of meals, personal hygiene support, mobility assistance); they are often referred to as Social Care. Without these the health of the individual with particular needs would be compromised and eventually fail. However, although social care and informal care are essential to improving health and preventing health problems, especially in an ageing population, there are still large gaps of knowledge in how best to organise this, and how best to combine it with health care. Specifically, improving health and general wellbeing via social care informatics, optimising the division of labour between different forms of care, is an underdeveloped area in both research and policy.

In 2009, the Standing Committee for the Social Sciences of the European Science Foundation claimed that “improving health and reducing health inequalities” was one of the main challenges that social sciences needs to tackle, especially given the demographic trend of ageing and the pressure this puts on care arrangements. In addition, the role of new technology and its implications for social processes and structures was put forward as an important cross-cutting theme for social sciences to focus on.²

Research on social care informatics is a good example of how the link between social science knowledge production and the application of this knowledge can be strengthened, and how to crucially improve the feedback between research and practice. This position paper aims at presenting the vision of a new paradigm of integrated care support for citizens’ health through linked social and health care. In the frame of the current EU flagship programmes such as ‘Healthy and Active Ageing’ and other initiatives in the area of ‘social innovation’, it seeks to set a common ground between relevant consumer, professional and governmental bodies.

Professor Sir Roderick Floud
SCSS Chair

1. *Constitution of the World Health Organisation, adopted by the International Health Conference held in New York from 19 June to 22 July 1946*

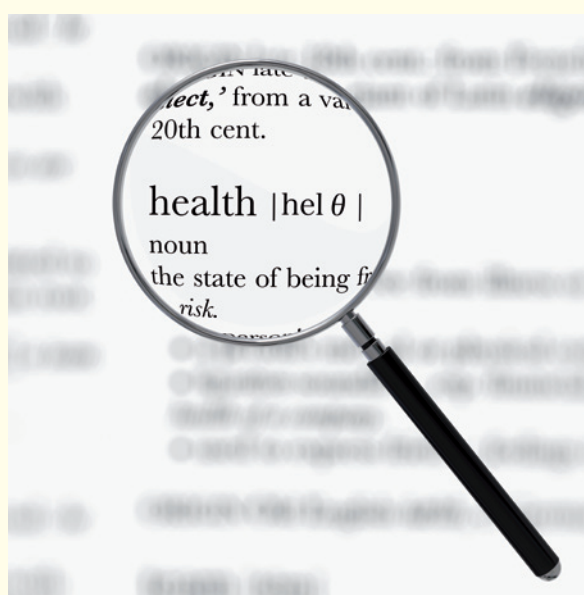
2. Cf. SCSS Science Position Paper *Vital Question, The Contribution of European Social Science*, p.23-29

Executive Summary



Europe faces significant challenges to its health and care services due to demographic change, being at the beginning of a large and continuing rise in the number and proportion of older citizens, while advances in healthcare mean that an increasing number of these and other adults will have enduring chronic health conditions. But for all citizens with actual or potential health problems, the maintenance of optimal health depends not just on healthcare services, but on support for nutrition, hygiene, mobility and shopping, socialisation, warm dry housing and other aspects of daily living, as without these health will be compromised and deteriorate. This demand surge is happening at a time when Information and Communication Technologies (ICT) are increasingly being used in other service sectors to enable consumer customisation and better resource management.

An objective for all health systems, and for patients, is to minimise hospital stays and maximise care at home, but hitherto the practical need to observe the patient's state of health has extended hospital stays. Similarly there is a drive to minimise – for quality of life and economic reasons – admission to long-term institutional care and instead extend support to enable living at home. Traditionally any support needed by an individual has normally been provided by family members, often assisted by the local community, while social services have been the fall-back provider when the family cannot support, either by direct provision or by mobilising specific services such as delivered hot meals. Housing agencies and other bodies have also had an important role. However, other demographic changes are significantly reducing the capacity of families to provide daily ongoing support.



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This means that health services are increasingly providing long-term monitoring and support to those living with chronic disease and frailty, while social services are increasingly needed to provide ongoing support. Many individual citizens are necessarily in receipt of both health and social care support, yet in all but a very few European countries these services are provided quite independently one from another, with minimal day to day liaison.

A number of drivers for change are now necessitating significant change, and the social sciences have a key role to play in enabling successful progress. At a macro level, across Europe the combination of the economic downturn and the demographic-led increase in demand means that health and social care services are under ever increasing pressures, while constant growth of services is not affordable nor will the labour market support ever continuing expansion.

Meanwhile, at citizen and societal levels two further and partially interlinked drivers are operating, but much less uniformly or equitably in their potential or their effects. The first is a general increase in consumer awareness of achievable personalised service standards, and availability of information both from service providers and from social and comparison sites and social networks as to reasonable expectations. Strong examples come from the holiday and civil aviation sectors, banking and insurance, and the retail sector including home shopping. No longer do consumers in general meekly accept what is offered, but instead seek what they desire from what they themselves can find out is available, related to published professionally set standards and from comparison of providers, and increasingly they are starting to expect a similar approach in the health and social care sectors. The second, and enabling, driver, is the rise in e-services and mobile devices, ranging from personalised monitoring devices, smart phone applications and service provider customer portals, through to the global unorganised but powerful knowledge base of the Internet. There are specific evidence sources on health and care matters, consumer-orientated and disease-specific internet sites, and a variety of blogs and chat rooms – the great majority helpful and well-intentioned, though with the ever-present risk of malevolent presences too.

This paper presents the case for systematic research activity in the social sciences, at European and national levels, to further the interlinked citizen-focused objectives of:

- close integration at delivery level of health care and social care support of individual's health,
- personalisation of care delivery including reasonable accommodation of individual choice,
- ensuring effective use of ICT applications based on user acceptability,
- bringing processes of consent, delegation, representation, coordination and privacy into the electronic era,
- ensuring respect for and teamwork with formal carers and the informal care team,
- ensuring equity in an electronic era regardless of digital literacy, assets and connectivity,
- examining stable and sustainable models of trusted infrastructure provision,
- establishing governance, authentication, management, and sustainability principles.

These are important research areas to ensure good delivery of services to people. They complement, and are as important as, health sciences research and health technology research including informatics research, since if the services do not reach the patient they do not have any effect.

The Problem



Most countries in Europe, as with most industrialised nations globally, are facing a significant increase in the number and proportion of elderly citizens, as shown not least by Eurostat (epp.eurostat.ec.europa.eu) and OECD (Colombo *et al*, 2011). Developments in health care mean that increasing numbers of people are surviving acute incidents such as cardiovascular disease or stroke to lead near normal lives, but often with a need for monitoring and specific health and wellbeing support, while advancing frailty brings its own needs for practical living support to enable continuing health and wellbeing. Whilst health services themselves are important for health, they are not the only relevant services – essential to good health is good nutrition, domestic and personal hygiene, access to technical aids, safe housing, and socialisation. In cases of frailty or impaired ability, including not just the older persons but those recovering from accident or illness or with a functional limitation, if these support services are not supplied then health will suffer. To compound this, dispersal of the nuclear family, and increasing economic activity of all family members, frequently reduce the opportunity for family support.

At the same time, in many countries the workforce available to provide health and care services is static or diminishing, due to cost constraints on levels of professional staff and to limited numbers available to undertake lower-paid caring tasks. Meanwhile, demand for improved support for health and wellbeing is being fuelled by increased consumer expectations of good service standards.

Thus both humanitarian arguments favouring effective support for vulnerable citizens in a civilised society, and increased consumer expectations and needs, each highlight the requirement for better

coordination and harmonisation of services within and between the health, social care, and other support sectors; and for involving the citizen and their informal carers as partners rather than simply being passive recipients of organisationally determined interventions. Economic pressures for increased efficiency underscore these needs, while making the task more challenging.

A potential and arguably much overdue contributory solution is to make better use of modern information and communication technologies (ICTs) to support and coordinate the delivery of services efficiently and effectively. The health sector has long invested in computing systems to maintain diagnostic results and subsequently in moving to electronic clinical records, and in recent years in specific types of telemedicine and of remote patient monitoring, but has made little advance in modern means of scheduling care delivery. Social care services have made even less use of client-facing electronic systems, while in housing there have been advances in some locations in remote activity monitoring and assisted living. However, each of these services is differently funded, mandated and regulated, and their information systems are quite independent, while furthermore the different sectors of most nations' health systems still tend to work in mutual isolation.

In a modern, service-orientated and information literate society this is not a defensible position. For the vulnerable citizen, expecting and deserving coordination of the support she or he receives, the provision of separate discoordinated and often conflicting services is not an acceptable situation. The demographic and economic pressures merely add weight to strengthen the demand that action be undertaken toward modernisation. Application

of information and communication technologies to enable citizen-centric integrated service is an overdue step. Some sectors, notably travel and leisure, retail and supply, are more advanced in the provision of such integrational ICT services, and study of their approaches may inform health and care sector developments.

However, although the technologies and the systems knowledge are becoming available, using them in the delivery of health and social care services is not straightforward given the complexities. Healthcare records are amongst the most complex and most sensitive types of documentation; social care records have similar sensitivities but are very different in nature (Rigby *et al*, 2008). All services have a strong and commendable commitment to confidentiality, which militates against their inter-coordination. Each of these domains, and their contributory organisations, has its own legacy of paper-based systems and controls, all of which will be challenged by computerisation and will have to be significantly re-engineered to benefit from the opportunities of digitisation and to achieve the goals of coordination and a client focus. Also, citizens themselves will have anxieties about the integrity of digitised systems, with their processing power, invisibility and perceived susceptibility to interference or misuse. Further, since each citizen's circumstances are different, the creation of an agreed partnership with informal carers will be different in each case, placing high demands on system design and user interface innovation and intuitiveness.

Consequent on these challenges, the key to progress and success lies primarily with social sciences research. Computing, communications, and sensing technologies can provide opportunities and can be further developed by technical research. However, as is regularly and repeatedly shown in many countries by adverse events (Gell, 2001; Ash *et al*, 2004; Ammenwerth and Shaw, 2005), effective implementation and use of digital systems in health is only successful if the people factors are researched and understood. Thus social science and technical research need to go hand in hand. Add to this the two further challenges of inter-sectoral coordination and a refocusing of service delivery to be citizen-centric and in partnership with clients and their informal carers as co-producers of health and wellbeing, then additional social science research needs become crucial. Thus many aspects need to be investigated in a social science and socio-technical research context as a prelude to considering implications for design and implementation of future information systems and supportive automation.

Technologically-driven solutions are ineffective; aspiration, belief and vendor promises as driving forces though common are ineffective or counter-productive; and citizen distrust is easier to create than allay. This paper specifies those issues needing a social science research focus to identify optimal ways forward in order to facilitate the coordinated provision of health and social care to citizens, utilising informatics support in a societal context.

Shared Acknowledgement of the Need for Action



There is increasing realisation of the need for research-based action rather than single responses. For instance, in July 2010 ESF funded an Exploratory Workshop convened by Professor Michael Rigby at Keele University on *The Challenges of Developing Social Care Informatics as an Essential Part of Holistic Health Care*, which was attended by 23 participants from 15 countries from health, social care and informatics professions and disciplines, together with legal, ethical, economist, and patient interests (Rigby, 2010). This workshop identified a range of issues that needed to be addressed, and went further with the production of a unanimous Declaration which *inter alia* “declared the fundamental importance of providing harmonised health and social care services that meet the extended needs of the individual, taking into account diversity in need, preferences, ability and support... utilising modern Information and Communication Technologies as enabling services, as part of a wider health and social care toolkit”, and it further “call[ed] on relevant authorities to initiate and facilitate a programme of Research and Development” which the document then outlined (Rigby *et al*, 2011a). The full Exploratory Workshop report and appended Declaration are available on the ESF website, www.esf.org, under the reports for Exploratory Workshops in 2010.

This theme was then taken up by the Organisation for Economic Cooperation and Development (OECD) in the context of its Smarter Health and Wellness initiative. Material from the ESF event, together with the Declaration reproduced in full, was included in a joint workshop with the US National Science Foundation in Washington DC in February 2011 on *Building a Smarter Health and Wellness Future*, and continues as a theme within

that work – see www.oecd.org/sti/smarterhealth.

Meanwhile, the European Commission is equally aware of the challenge arising through the increase in the elderly proportion of the population, and the potential major effects on health and care services. It has established a priority initiative, the *European Innovation Partnership on Active and Healthy Ageing*, which is receiving high impetus (http://ec.europa.eu/research/innovation-union/index_en.cfm?section=active-healthy-ageing). It has also set up the Age Platform (www.age-platform.eu) to bring together some 150 organisations of and for older people. Several Directorates of the Commission are giving priority to calls for initiatives which address this broad area – particular projects worthy of note in this context are FUTURAGE (futurage.group.shef.ac.uk) to create a roadmap for future research into the issues of ageing within society, and Bridging Research in Ageing and ICT Development (BRAID) (www.braidproject.eu), considering the interface between older citizens and ICT. There is also a range of specific projects and research calls on selected themes within the Framework 7 programme of DG Research and the work programme of DG Communications Networks, Content and Technology (CNECT) (formerly part of Information Society). While several of these have included ICT interfaces or user acceptance of health informatics applications as components, none of these so far has addressed directly as the focal point the specific, sensitive and complex issues of researching in detail the case for, acceptance of, and professional and citizen user requirements of systems which facilitate the coordinated delivery of health and wellbeing support. It is this specific research as outlined in the ESF Exploratory Workshop, and underscored

by the OECD activities, which must be the starting point both for development and implementation of effective holistic systems, and for the necessary related public understanding and debate. These issues are now appearing amongst the objectives for the final calls of the FP7 programme, and are to be anticipated in the successor Horizon 2020, but still focused at the local project and demonstrator level rather than at universal health and care policy and system level.

The Core Societal and Care Provision Issues



There is an inter-connecting range of societal issues including demographic factors which is necessitating significant change in how health and wellbeing are supported in a dynamic society. At the same time, while ICTs offer a potent and under-capitalised range of assistive solutions, their introduction also raises tensions and conflicts. Above all, as the above-mentioned activities have identified, there is a dearth of evidence as to the best ways forward in developing and harnessing informatics support, even using existing known technologies. This next section highlights the societal issues, many needing deeper understanding, consideration of which is an essential precursor to successful application of ICTs, because modernisation through informatics must support the new societal dynamics, values and means of working so as to ensure relevance and effectiveness. The subsequent sections then identify the issues raised by informatics applications themselves which need social science based research and action.

Demographic and Societal Change

The core issue and one of the triggers of the need for action is the steady growth in both numbers and proportion of persons aged over 65 years, and over 80 years, in Europe, as shown in Figures 1 and 2. Whilst this is a success for society in creating greater longevity for European citizens (achieved through better incomes and nutrition, housing, education, environment, safety and health care), it brings with it the price in the health and care sector of not just a rapid absolute rise in the numbers of older citizens, but a rise also in the proportion of the population who are older or very elderly. As a result the ratio

of 'productive' adults to older citizens is subject to significant change, shown in Figure 3. However, this is not solely an issue of ageing, and younger persons with chronic conditions or illness must equally be supported sensitively as well.

Thus current patterns of health and social care service are not sustainable in practical terms. Reduction in family size adds to this, not least at the family level, as does increasing parental age at childbirth giving less overlap between successive generations.

At the same time, modern society's opportunities including greater wealth and improved travel, elimination of rigid political boundaries, and the right of freedom of movement within the European Union and its neighbours, coupled with economic and educational migration, have resulted in the steady decline of the close-knit and co-located satellite family as younger generations locate away from the parental home. As a result family support for older family members in terms of shared accommodation or nearby support is increasingly scarce, and instead the older citizen is often left alone in a large family home from which the grown-up children have moved to education, employment and marriage long distances away. Isolation adds to frailty, and creates a new demand for support to ensure wellness.

A third demographic change is the reduction of the traditional mother and housewife role, whereby home-making including looking after children and supporting older family members was a full-time activity for a wife, or sometimes an unmarried older daughter. Increasingly, all adult family members choose or are economically drawn into full-time education and employment, and gender-based restrictions are rightly reduced, while more

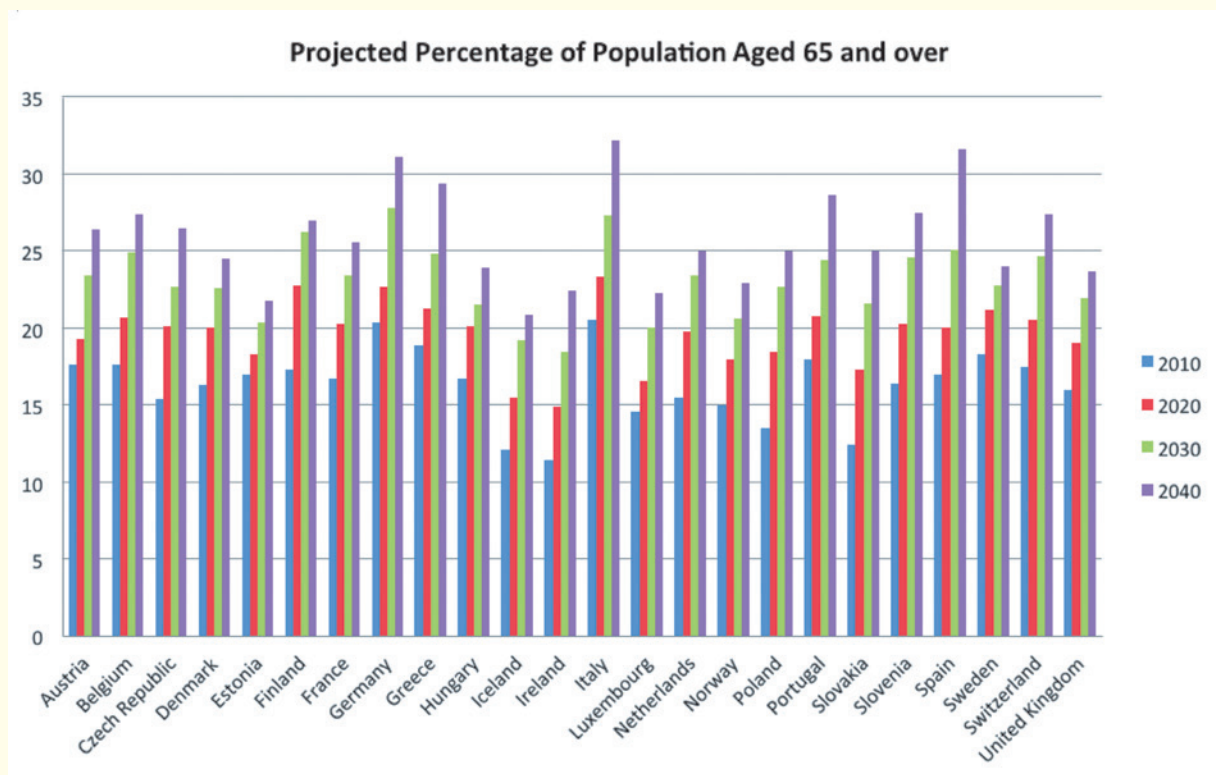


Figure 1. Projected Percentage of Population aged 65 Years and over

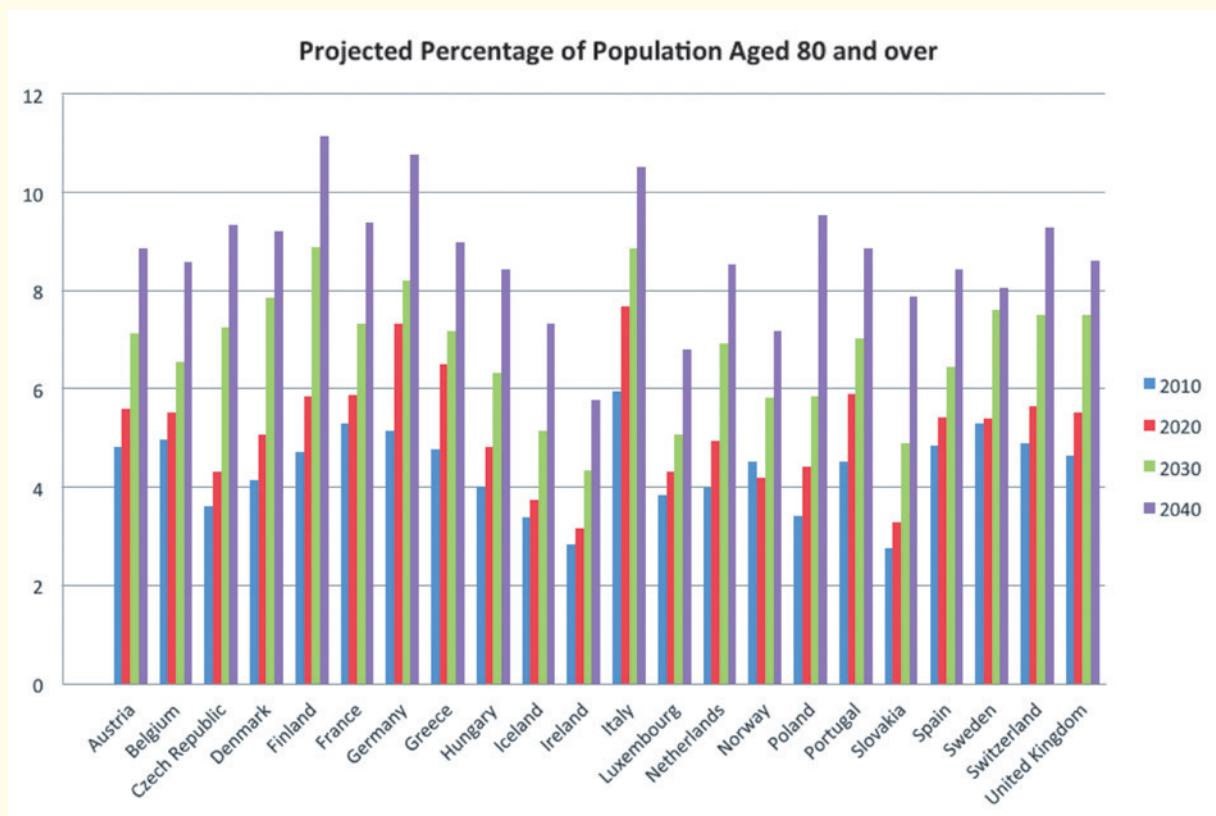


Figure 2. Projected Percentage of Population aged 80 Years and over

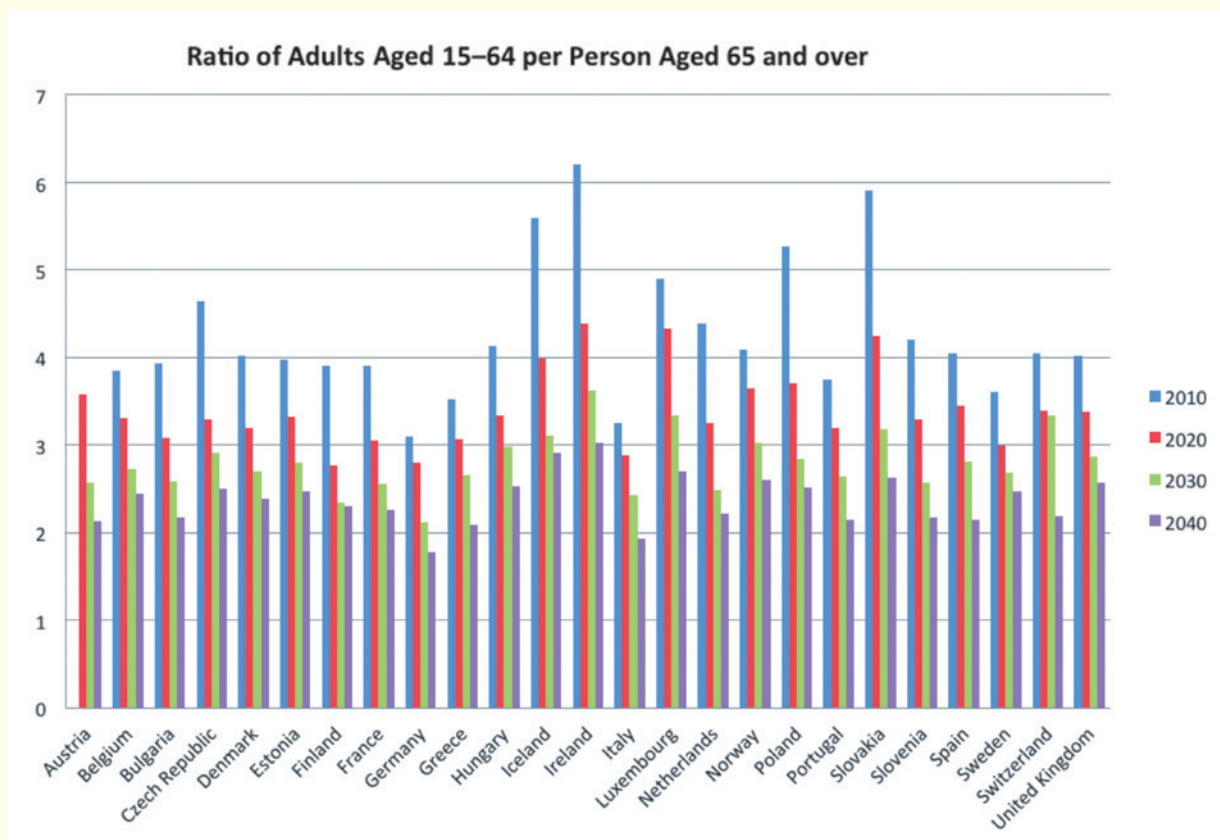


Figure 3. Projected Dependency Ratio of 'Active Adults' to 'Elderly'

children are extending their period of education, so even within the household there is much less care-giver time available. This is not necessarily an adverse change, but it does reduce family support for dependent members.

Chronic Diseases, an Older Society, and Increasing Frailty

Medical science linked with improved living has yielded increased survival of episodes of acute illness, though frequently with some reduced personal functionality or continued elevated disease risks. Acute diseases such as heart attack, stroke or many cancers now have much better survival rates than a decade ago, and even better rates than two decades ago. Similarly chronic conditions such as diabetes are better controlled and their side-effects better managed. The positive outcome of this progress is that many people who in the past would have died, now survive for many years of normal or near-normal life; the negative outcome is that many of these survivors may have some impairment to normal life, and many will need regular monitoring. Some of this monitoring will be professionally led and technically based, but in the philosophy and

practicality of co-ownership and co-responsibility, much of this should be self-monitoring – raising issues not only of ensuring easy access to service support, but also issues of education, awareness, competence and commitment, and also ethical issues when individuals decline to act and thus let their health deteriorate to the ultimate cost of their health provider organisation and its funders.

As more people survive into their ninth and tenth decade, and indeed many will become centenarians, so the number of persons with physical and mental impairments caused simply by frailty will increase, exponentially. These people are not ill, yet their health is seriously at risk if they do not get support with daily living; in many cases this support needs to take account of medical factors.

Key Demographic Facts

EU27: Population over 80 years will grow from 5% in 2010 to 11.5% in 2050.

USA: 50% of all adults have a chronic disease.

USA: Number of people with Alzheimer's Disease will grow by 50% in 30 years.

Co-ownership of 'Health' and Co-responsibility for Health

Concurrent with this the locus of responsibility for personal health is changing. No longer does the citizen passively look to the medical system for advice and cure, based on a significant knowledge differential. Better education, knowledge about the effect of lifestyle and other person-driven health determinants, and widespread availability of that information in many forms of media, mean that the citizen should take on a major responsibility for his or her own health (Russell and Smith, 2003; Jacob, 2012). Even when disease, accident or infirmity mean that the power of modern scientific medicine is necessary, the citizen is now involved not just with compliance with treatment, but increasingly in self-care (Dinesen *et al*, 2012) as well as discussing treatment options, planned outcomes, and pharmacological options and possible side-effects (Von Korff *et al*, 1997; Newman *et al*, 2004) – with the citizen able to get validation and other opinions from the internet and other sources (Andreassen *et al*, 2007; Kummervold *et al*, 2008).

This changed pattern of health ownership is particularly pertinent, yet particularly challenging, when it comes to older citizens and others with chronic diseases. Aspects of choice and of informed decision-making increase at a time when issues of confusion, forgetfulness, and frailty may also increase (Smebye *et al*, 2012). Denying personal autonomy on grounds of age or infirmity is indefensible, but so is expecting frailer individuals to make all choices and initiate communication unaided. Ethically guiding an individual who is feeling personally vulnerable to illness while also confused by modern society, and with no geographically close family, is challenging and needs clear rules and guidelines as well as available support services. This may necessitate the development of new competencies of awareness and reflectiveness in care professionals, to enable perception of the possible difference between the professional's moral understandings and those of the individual, encompassed also by organisational and societal values and assumptions.

This brings in another aspect of co-ownership of health, or co-responsibility for it. Since many aspects of daily living are necessary for maintenance of health, including nutrition, hygiene, exercise and socialisation, when frailty or infirmity make these difficult the person needs support with tasks such as cooking, personal hygiene, domestic cleaning, shopping for essentials, home maintenance or social contact. Provision of this support has been a

normal part of family life, but as families become smaller and disperse, and as spouses themselves may become less able to support fully, the provision of formal services becomes necessary to maintain health. Thus social care, housing and other services become essential contributors to the health of the population, yet in most countries come from a quite separate complex mixed market which is still immature. At the individual level these services can be essential to health, and their staff may be the most frequent observers of the citizen's state of health and wellbeing, but in nearly all countries they are mandated, funded and provided quite separately from the health sector, with whom they may have little contact at service level or about the individual client.

Carer Partnerships

Traditionally health systems have viewed the patient as a client in isolation, with the patient indicating the degree to which he or she wanted information shared with others – including their spouse. That confidentiality is important for a trusting professional–patient relationship. But treating the patient in isolation is inappropriate if done rigidly. Increasingly, informal carers are being taken into partnership in particular ways, such as administering specific injections. Yet too seldom is the question of whether or not a spouse is providing adequate health-related and daily living support, or indeed expressing emotions such as anger or helplessness, being taken into account.

In this respect social care services operate very differently. Their role is to assess the individual in their physical and social context, and to identify housing inadequacies or the need for special equipment, but also the context of family, neighbours and friends. These latter are people whose help is important, but who themselves may need help either for their carer roles, or to cope with the impact of the client's needs on their own lives. Further, there may be a vulnerability in a carer which leads to a 'care for the carer' need, which is based on the initial individual's problem as it impacts on the second person – in effect a 'co-owned' need, and one creating potential challenges of recording and of resourcing.

What is important in a modern informed society is to welcome and accommodate informal carers as partners with the client patient and with the formal health and social care services. This help may be in active roles, such as cooking or providing assistance with personal hygiene, or it may be as an observer best able to report back mental, physiological, or behavioural changes. For this new carer partner-

ship informal carers need support, and they also need the consent of the citizen; but further, they need an information interface with formal systems (McWilliam *et al*, 2004; Caress, 2009).

Commensurate with this, informal carers themselves need opportunity for a form of assessment, and for this to be recorded – not only as to their skills, capacities and anxieties, and need for advice or support, but also any risks they may present, since unfortunately not all family members or other carers may have the best altruistic motives or caring skills. So carer partnerships are important ethically and practically, but they also raise new challenges that require researched solutions.

Finally, in the new modern idiom, Information and Communications Technologies mean that some of these informal carers can and may be remote – a distance or even a continent away, but still keeping in touch with the older family member they have left behind. They cannot offer physical support, but they can be part of the virtual support team, and may be able to mobilise others especially if they are a close family member. But how to involve distant virtual carers (possibly in another jurisdiction), how to include them in the support team but not be inappropriately diverted or directed, needs considerable research and debate.

Integration of Care Responsibility

These phenomena make it increasingly important for the health and social care services to work in tandem, as a composite virtual care team, often linked with the informal care team of relatives and others, to support the individual through further contented years. This means significant changes in attitude and in information sharing within the health sector, between health and social care, and with other agencies and with family carers.

The rigid traditional boundaries between primary health care and secondary care mainly in hospitals, with also an overlay of highly specialised tertiary services, is needed in terms of special expertise but the results and the ongoing care must be shared and coordinated, both for efficiency reasons and to ensure integrated delivery. But so too must the various branches of social care work harmoniously together, and as a partner with health services.

This will require new concepts of cooperation, coordination and collaborative working – not just in the interests of providing the best service to the individual based on better understanding of realistic patient preferences rather than standard service responses, but also on grounds of efficiency and

of ethics (Von Korff *et al*, 1997; Caress *et al*, 2009; Dinesen *et al*, 2012). ICTs harnessed appropriately will be essential tools, yet paradoxically the most frail or vulnerable may also be persons naturally least comfortable with digital technologies, providing another research necessity of some importance.

This will, in turn, require greater social science study as to how change practice from silo working to shared working (for instance see <http://common-well.eu/beyond-silos-integrated-ecare/>); and on the other hand to ensure that the public and individual patients trust the methods and the outcome of this collaboration – the negative connotations being those of collusion, reduced patient voice, and of secret messaging of private data.

Personalised Care and Personalised Medicine

All care within health and social care is considered personal, both by the recipient and by the provider. Confidentiality and trust are manifests of this personalisation. But in fact, hitherto much of that personalised care has consisted of combinations of very standard responses in the light of diagnostic procedures and other rule-based assessments. One example is the comparatively standard doses in which pharmaceuticals are prescribed, even though each individual's metabolism, absorption and side effect reactions will vary.

Increased recognition of the autonomy of the patient, co-ownership of therapeutic options and informed expression of choice, and the ability of modern record systems to communicate and display virtually to all care partners regardless of location, will enable and indeed create greater expectations of much more personalisation of treatment and of care delivery. Components of care may be standard, though from a much richer and subtler range of options, but also arise from innovative yet justified personal choices, while their packaging into a care plan is personal in every sense, and informatics is a key enabler. This personalisation should be tailored for, and by, the individual across the range of services to provide trusted holistic support.

The increased incidence of co-morbidity, as longstanding conditions co-exist with newer ones, will deepen this necessity. The autonomous individual treatment by different independent specialties separately for each concurrent condition should no longer apply – there should be understanding and interaction between services. To achieve this there must be information sharing across care teams, yet means must be developed of enabling the citizen to

have some control – and an awareness of the risks of any confidentiality barriers erected. Increasingly informed citizens, even if not fluent in the biological and pharmacological sciences, will expect evidence of this interaction.

To this complex scene must now be added so-called Personalised Medicine. This is the somewhat inappropriate title adopted by those seeking, very rightly, to harness the rapidly increased understanding of the human genome, and the consequent ability to plan care based on analysis of the individual's genetic composition. It is anticipated that in future a whole range of personal assessments will be possible, from the propensity to developing a specific cancer (already some women at very high risk are offered prophylactic mastectomy to protect – at a high price – against contracting breast cancer), through to anticipated dose reaction to specific pharmaceuticals; this is becoming known as stratification of care. This is truly medicine personalised to the individual, but it must not swamp out other personalisation – to choice, to personal lifestyle and social support circumstances, and other personal factors. It also raises huge ethical and social issues, for instance as individuals discover that their genetic composition is not what would be the case based on their understanding of their blood lineage – a range of difficult issues have to be addressed here from partner unfaithfulness through to egg and sperm donation which may have been 'forgotten' as parents rightly considered the resultant child as their own. How to handle these situations, and who to protect, needs much deeper study – there will be innocent victims as well as beneficiaries of these processes (Rigby, 2012).

Consumer Expectations of Patients and Society

Throughout the fabric of European society formal services are increasingly prominent and essential. Retail and financial services, transport, insurance, leisure and vacation and real estate provide some examples of the essential role of services in modern living. With the advent of modern technology and wealth, new services such as civil aviation have grown rapidly to become effectively available to most citizens, and these set customer expectations for personalised interaction with large technology-based services.

Many of these services are safety critical, while most are wellbeing critical, and thus the health and care sectors can no longer claim uniqueness in those respects and hide behind a veil of secrecy and old

technology. In all service sectors consumers individually and corporately expect, with justification, an open process of setting and adherence to standards of service delivery based on equity and transparency. Moreover, increased education, and the availability of information from on-line and other sources, means that the consumer is much better able to identify reasonable expectations and assess apparent failures. The health and care sectors are no exception to this expectation of service standards and accountability, but they have the additional challenges of collectively having to provide a service to all, adjusted to each person's individual needs and characteristics.

Ageing in Place or a Place to Age?

Location of ageing has a significant effect on integrated care delivery, and on costs and budgets. There are strong arguments in favour of people growing old in their familiar lifetime home, including awareness of surroundings as frailty advances, and established social and community support. This necessitates delivery of care support to those homes, which at the same time may have disadvantages of being out-dated, and possibly colder, damper, more difficult and expensive to maintain and more risk-bound than more modern housing. It also results in a family-sized house being under-occupied by one to two people. In contrast, clusters of housing designed for less mobile citizens, including 'smart homes' equipped to facilitate monitoring, can bring the advantages of ease of living, greater safety and efficiencies of service delivery but at the cost of the elderly individual's relocation to unfamiliar surroundings, and such developments require significant capital investment.

A further balance is between domestic living of either type, or a move to residential care or nursing home care. Choice is often strongly influenced by availability – itself linked to investment patterns and regulatory frameworks, and affordability in a complex funding scenario. A major but under-addressed issue, however, is how health and social care delivery are undertaken, and financed, in these different types of residential setting. In principle, specific forms of health and care support can either be given by staff linked to the residential facility, or by the domiciliary care staff of the local health and care providers visiting the citizen as the home is their place of residence. For either option, strong issues of collaboration and coordination, including the home staff as members of the virtual care team, are vital and deepen the inter-operability challenge.

Too often regulation, accreditation and inspectorial issues, as well as budgetary drivers, dominate these policy decisions ahead of scientific evidence of which solutions provide the most effective and efficient care, and which provide the best health maintenance support to the individual. These questions are additional to the core debate between more intense support to a domestic home or admission to a residential facility, and the citizen's realistic preference.

Homelessness is a further dimension. Unfortunately, in all parts of Europe individuals, often older, can be found sleeping in vacant spaces or shop doorways. Delivering health and care support to these individuals is a challenge, yet their need is great, and ethically and morally they cannot be ignored. Even when responsible health support agencies are identified, record keeping and delivery planning are challenging. It would seem inappropriate to give the address of the shop in whose doorway a homeless person regularly sleeps as their care delivery location, but to exclude the needy individual from care delivery records is even less appropriate. Until homelessness is eliminated, greater study and solutions to delivering health and wellbeing support to these individuals is urgently needed. Care continuity support must also be assured to those in crisis-supporting facilities such as refuges and hostels.

Workforce and Related Issues

In many countries the effects of demographic change and of skilled service specialisation have made recruitment of adequate numbers of new entrants to the formal health professions difficult – a situation currently ameliorated to a degree by the economic downturn. Many countries are dependent on maintaining their full health workforce establishment only by recruitment of doctors and nurses from other countries, within and outside Europe, a situation bringing its own quality and ethical issues.

In social care and other support services, including private recruitment by citizens of help at home, the situation is even more challenged. Though essential, many of these services are low skilled in terms of formal qualifications, do not pay well or have no major career opportunities, and therefore are not attractive forms of employment – a situation exacerbated by the pressures on the budgets of public and insurance providers who have to stretch scarce funds. A partial solution in many countries has been to recruit such low skilled workers from residents of poorer countries, but not only does this raise regulatory and ethical issues, but increasingly

public and economic pressures are combining to cease this employment migration (Colombo *et al*, 2011).

The net effect is that at the same time as pressures for domiciliary support services from social care to maintain health are being increased both by demographic factors and by the drive to reduce length of stay in hospital, so recruitment and retention of competent caring staff is difficult, compromising service provision. To counterbalance this, the use of informatics systems to increase efficiency and added value, and to enable some routine visiting to be replaced by appropriate remote monitoring, becomes an attractive proposition. But success in this field requires sound social science research, to ensure that client comfort and caring are enhanced not reduced – remote sensors can tell if a kettle has been boiled but not if a hot drink has been made and drunk; electronic records can show of a visit was made as scheduled, but not the quality of the inter-personal interaction.

The Active Elderly and other Volunteering

However, at the same time that health-related services are being put under pressure by demographic change, so the same demographic change is producing a cohort of fit and able retired citizens with large amounts of free time, and often a desire to be active and useful. Leisure opportunities will absorb much of this freedom, but many such citizens seek a soci-



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etally valuable outlet for some of their time, and indeed volunteering is a well-established concept, largely uncoordinated but valuable – a potentially rich new social capital.

The act of volunteering by retired people or younger generations contributes to society, but it is primarily a personal decision and activity. Assisting a neighbour or a former work colleague needs little organisation. But for volunteer support to the health-related needs of citizens to be societally effective, particularly for the most socially isolated and the most dependent, some form of organisation is desirable. Whether for transport assistance for treatment and other appointments, to arrange shopping, or to deliver a hot meal, there needs to be a clear yet simple and reliable system to ensure delivery of promised support, and which can also enable appropriate co-ordination with more formal services. In many cases such voluntary activity needs some way to communicate systematically with formal services about services to individuals – for instance to confirm that a support activity has indeed been carried out, or to advise that a person seems to have a new problem – and in these respects interface with the information systems of formal service systems seems necessary, and study is needed to identify optimal solutions.

Research into volunteering and its motivation is a recognised important but young research area (Lauber *et al*, 2002; Musick and Wilson, 2008). Research into its stimulation, organisation and regulation without dampening the commitment, is even less developed but very important, as is understanding of how to build partnership with formal services in a monitored and accountable way.

The Social Media Phenomenon

The last few years have seen an explosion in the use of social media by ordinary citizens. Uses can range from keeping in touch with relatives, to supposed key roles in the election of a president in a large democracy, to stimulating citizen unrest to overthrow non-democratic regimes. And in many countries social media footage passed to broadcast and print media has had significant impact. Furthermore, these social media increasingly can be accessed in any location at any time by use of smart phones – though it is important to note that not all citizens are either comfortable or fluent with the use of these social media, so that what is a potentially positive tool for many must not be made compulsory as the means of interacting with all dependent citizens.

Health care has witnessed a proliferation of condition-related online communities, providing consumers with the opportunity to share experience and expertise. These communities provide a range of new value propositions offering health care consumers opportunities to undertake self-service activities, manage their own experience and, in some cases, be independent of health care professionals. These communities offer a decentralised opportunity with the freedom to explore outside professional boundaries, increasing access and seeking to overcome information asymmetries. They also offer an alternative and community-owned co-created knowledge and experience store. The outcome of involvement in such communities can lead to consumers adopting an informed engagement position as a new basis for health relationship management (Laing *et al*, 2011). These communities are by no means the dominion of the young ‘Millennials’, but are often serviced by consumers in much older age groups, offering their time freely and willingly (including technical expertise). Diverse social media platforms support the proliferation of these peer-to-peer services in new and challenging ways that impact on formal services.

Serious study of the potential to use social media as a planned element of organisation and provision of health and care support is at very early days and needs significant social science study (Lau *et al*, 2011; Paton *et al*, 2011). Furthermore, the citizen must be enabled to best use such tools to enable health management, but must be protected against adverse effects, and this too needs research and resultant action (Rigby *et al*, 2011b).

The Economic Backdrop

Exacerbating these societal issues are the general economic pressures. These can be seen as threefold, though with interlinkages. First the cost of medical treatment, and all care, is increasing. Primarily this is technology led, with new and expensive diagnostic methods and treatments, intensive in capital, specialist personnel, and ongoing often life-long costs such as expensive pharmaceuticals. But also, across all care services, basic remuneration must rise from the frequent very low levels if staff are to be recruited and retained, and if the necessary skills are to be acquired and recognised to give the necessary competent workforce (Colombo *et al*, 2011).

The second economic factor is that the ability of citizens to contribute financially to their own support, which in many cases has been rising, will fall back as longevity eats up savings, as pension sys-

tems come under an increasing variety of pressures, and as extended families are less able to co-support financially. The third factor is the overall global economic downturn, which has reduced the tax base for public services and the wealth base for insurances.

The immediate pressure therefore is for cuts in budgets, and for increased efficiency which often manifests as rationing. But cuts in support for health and wellbeing to those with needs, as well as being morally difficult, in the longer term is counter-productive if the result is poorer health necessitating deeper and more expensive responses. Instead greater targeting, effectiveness and efficiency are needed, to ensure that good and appropriate services reach each individual to ensure optimum maintenance of their health – and this means investment in modern methods of delivery support, particularly innovative use of ICTs.

Financing Philosophies and Mechanisms

It is important to acknowledge the challenges of health and care systems financing, as they form a backdrop to the issues in this paper, and to the provision of informatics support to integrating the care delivery processes. Financing patterns are a societal issue in that most populations are reluctant to see radical change to the familiarity of the principles of their national health system, yet at the same time recognise the challenges in the detail, and the uncertainties caused by change to the status quo including in organisational and patient inter-relationships, not least personal affordability. However, these systems are both complex and specialist, and therefore are not covered in depth here so as not to overshadow the main issues.

There are many different health funding systems in the countries of Europe, including several models of publicly funded system and several models of insurance-based systems, each with different attitudes to supplementary patient-purchased private provision. Social care is differently funded in different countries, though with only a few exceptions social care funding is very distinct and differently sourced from that for health care despite the fact that the two services support the same people and have key inter-dependencies. Supported housing provision is funded differently again.

Secondly, in each country there is a different system of organisations providing care, each of which has to have its own financial system. This can include different sets of organisations within the public sector, different private and not-for-profit



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providers, and the sub-contracting in any system of some specialist provision to commercial providers. This complex plurality applies in the health sector, and even more so in the social care sector.

Finally, there are different budgeting and accounting systems as to how providers are reimbursed for care given. For instance, this may be by block allocations or contracts for a given amount of work; be on a nominal cost per service or per case; by costing formula such as diagnostic related group (DRG); or by direct billing. The core issues of this paper are concerned with the human issues of care delivery, the role of technology support, and the social science research needed to ensure this is effective yet acceptable. But the complexity of budgeting, financing and charging, and the demands of these financial needs for person-level activity data must be highlighted here (Hill *et al*, 2008). Above all they have an impeding effect both on organisational change and on creating new patterns of delivery such as remote monitoring replacing some home visits, or one worker reporting to two different care-providing organisations. These are societal issues in so far as populations are likely to be conservative regarding changes to traditional financing systems, and to be suspicious of contributing to financial transaction-related data.

Plurality of Provider Choice and Porosity of Borders

Finally in the summary of societal issues, increasing numbers of countries are moving towards formal choice in health and social care systems, driven by interpretation of consumer expectations of choice and the avoidance of insensitive monopoly, and by political belief that this will moderate the rising costs assailing besieged budgets. Patients are not consumers in the economic and libertarian sense, since they have needs not of their own choosing, and limited sources of supply of highly specialist services, for which they may need guidance on choice. However, this does not diminish their rightful expectation of respect, autonomy and choice wherever possible, together with optimum achievable quality. At the same time they may need guidance in exercising their treatment and care choices. Whether such choice be through internal market competition within publicly funded systems, or through choice of cover and provider in insurance-based systems, care will perforce have to be personalised also to match provider availability and insurance cover – even for identically presented situations. And there will need to be objective quality standards with related governance and audit processes to protect the vulnerable consumer, and also to ensure equity for providers.

Modern economics and accounting, governance and regulation, and information systems are the enablers of such plurality and choice, assisted by management science. This is a major area needing social science research as to acceptability, personal professional and organisational provider behaviour, standard setting compatible with variety and choice, and how to ensure adherence to principles of equity and quality while enabling needs-targeting of services to best effect and best satisfaction.

And at the same time health care is becoming global, in two senses. The specific European contexts are the right to travel and to the right to receive care in another European country. This is most applicable and subject to strong policy development for health treatment, but means that health care and its systems cannot be impeded by national borders within Europe – though the practical issues regarding medical history availability and post-treatment care with different systems and languages are another matter. The wider context is that internet health services and telemedicine can be provided worldwide and accessed by any citizen. It is quite feasible that remote health and care monitoring could be provided across borders in the near future. These possibilities raise many new issues.

The Necessary Paradigm Shift – Ensuring the Success of ICT as the Enabler



This meeting of clients' and carers' individualised needs through delivery of integrated health and personal care across provider boundaries, managing the standards and accounting of mixed markets, keeping personal health and care records ethically interfaced so as to yield holistic care, and managing the service organisations based on actual care delivery, will be highly dependent on computer systems, modern communications and system peripherals with their interfaces, automated rules and algorithms, professional, carer and client interfaces, system functionality design, and education and training. And secondly, ICT solutions through various forms of monitoring of physiology and well-being will bring in a further new vital dimension of informatics to shared care.

Europe progressively has sought to set itself as an 'Information Society'. Information systems, computer applications, and virtual on-line working are ubiquitous, and are essential underpinning to most modern services and many occupations. The European Commission, particularly through the Directorates for Research and for the Information Society, is actively seeking to widen innovation and application. The most common and generally accepted of these are in domains such as retail services, travel, insurance, and banking, or are generic for specific functions such as accounting, payroll management or stock control.

In the health domain some informatics application areas are well developed, such as patient administration systems and digitised diagnostic images; other areas are developing rapidly such as electronic records, prescribing and types of telemedicine. Some other areas such as Ambient Assisted

Living and smart housing are also making strides. The European Commission is actively supporting technical research and innovation in all these. But the pressure of combination of demographic, economic and societal expectation, coupled with the ethical imperative to achieve the right to health by ensuring availability to all options to achieve the universal objective of Health for All, means that health and care services have to undergo a sea change to become truly information rich and informatics enabled, as identified by OECD (Rigby and Ronchi, 2011). And while research and innovation in health informatics technologies are important, success will require tailoring to service delivery need, and acceptance by users of all kinds, and this will need social science research as well as technological research, and validated effective roll-out beyond high profile pilots (Rigby, 2006).

Evidence-Based Health and Care Informatics

To achieve the integrated care delivery paradigm shift, the beacon of Evidence-Based Medicine (Sackett *et al*, 1996) must become Evidence-Based Care (as for example the Scottish Centre for Evidence-Based Care of Older People – <http://www.gcu.ac.uk/jbicentre/>), delivered by evidence-based practice (Aveyard and Sharp, 2009). The evidence must be not just that of evaluation of treatment options in clinical and care research, but must be the evidence of the most effective use of available resources, in a societal context, delivered optimally to meet the dynamic needs of each individual with

a need for support for their health (Georgiou, 2002). Information systems and ICTs are the essential underpinning, but specific systems and applications should only be deployed based on evidence of their safety and effectiveness, as a result of a necessary new paradigm of Evidence-Based Informatics (Ammenwerth *et al*, 2004; Ammenwerth, 2010). And a truly rich research-grounded evidence base in the human and societal context has yet to be developed.

Some long-standing assumptions will have to be changed – the focus needs to be not on records but on interactive information services including both recording and delivery systems. The vision of the cradle to grave (indeed, arguably conception to autopsy) single electronic record is pointless, unwieldy and unachievable; what is needed is the assembly and presentation of the key facts in the right place at the right time for a particular purpose, sometimes on demand and sometimes proactively. This is more effectively achieved by data from different systems, including monitoring data or derived alerts, being kept in defined systems until they need to be integrated, and this then being achieved by fit-for-purpose processes including transmission to key individuals of alerts, and controlled environment broker access on an as-needed and as-authorised basis to information currently required for a specific decision or other purpose (Budgen *et al*, 2007). Automation of paper-driven processes will fail as this will not harness the new science nor produce the new opportunities – paper-based processes were designed to work within their own limitations. What is needed is the design of new

systems of application and delivery harnessing the full potential of ICTs and informatics, but with the balancing provision of new monitoring and control mechanisms.

There is also a need to consider the provision of and access to information and associated ICT tools as a care service in its own right – enabling citizens to become actively engaged in their own care, assisting them in making informed choices, and helping them communicate effectively with service providers and their care team (including remote informal carers.) There are expectations that citizen- and carer-focused knowledge bases – which may include forums for sharing experiences and feedback on services and service providers – will emerge as online services develop, reflecting those increasingly available for other sectors, such as travel, or entertainment. One example is PatientsLikeMe (www.patientslikeme.com) which is unashamedly independent of health service systems. Citizen eHealth services, interlinked with professional eHealth services, do exist but are limited, and to support both clinical work processes and empower patients to effectively handle self-care a number of issues remain unsolved (Koch and Vimarlund, 2012). Challenges will arise in ensuring that these kinds of services retain validity and safeguard their users, through managing and publishing the provenance of data and addressing concerns for confidentiality and privacy (Rigby *et al*, 2001).

Finally, digitisation of data on care delivery and outcomes, held in personalised distributed records, should be exploited by a new generation of learning health and care systems, in the way that other service and manufacturing sectors have developed means of learning from the pictures of demand, delivery and outcome to become smart organisations – large increases in knowledge can be made by harnessing the information locked away in health and care systems (Friedman *et al*, 2010; Grossman *et al*, 2011; Friedman and Rigby, 2012). The challenging difference in health and social care is firstly the very confidential nature of the data, necessitating strong access controls and ethical rules; and secondly the general lack of a trusted yet smart overarching gateway organisation, along with the need to change the current organisation-centred work and delivery routines.

Thus while on the one hand change is necessitated in health and care systems by demographic change, consumer expectations of quality and the drive to apply new scientific discoveries, the nature of each of these creates a dependence on a new generation of informatics applications. But the success of these, from the system design, through



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the functionality and innovative and intuitive user interfaces, to the permitted controlled sharing and the necessary rigorous controls and governance mechanisms, must be based on social science research to determine what will be workable in practice, acceptable to each type of user, and will create smart but effective systems. Clinically driven initiatives may demonstrate the potential in controlled settings, ICT initiatives may demonstrate technical potential, but as is already shown by many underperforming or failed showpiece systems (within and outside the health and care sectors), it is the adequacy of the social science research and its interpretation into solutions for general roll-out which creates success.

Facilitating the Support Potential and Structural Impediments of Modern Smart ICTs

Modern information and communication technologies, and related computing system techniques such as algorithms, scheduling protocols accommodating attributes such as urgency and priority, and purposeful data mining, are continuously developing. The health and care sectors have in general been slow to adopt new information concepts and methods that do not fit with previous paper-based logic, not least because of legitimate issues of ownership and clinical responsibility where new service models or responses are needed to partner the new technology-based opportunities. It is not the technologies and techniques that are the barrier, but the human, professional and system changes necessary. Even within the health sector, negotiating new service constructs and responsibilities (including standards, accountability, reimbursement, information system provision and governance) is a challenging task, with few robust examples of trusted and empowered agencies able to develop and implement national evidence-based constructs – though there are good sub-national examples such as Andalucía and Scotland.

Add in social care and the justifiable vision of integrated care support to the individual citizen, and the separate legal and funding structures between health and social care form another major barrier. In nearly all countries the only place where they come together is cabinet-level government. The most notable exception is Finland, with its integrated programme of e-health and e-care, and a concomitant evaluation programme. Clearly this problem is an issue of social and political constructs, not one of technology nor of clinical science.

Finland's Strategy

- National eHealth Strategy including patient-accessed electronic health record (www.kanta.fi)
- National eWelfare Strategy (www.tikesos.fi)
- National eGovernment, eServices and eDemocracy programme 2009–2014 will include e-health, e-welfare, pHealth, self-care, citizen care diary, and citizen portals
- Dedicated evaluation project (KaTRI)

Health and social care are both municipal responsibilities in terms of planning and delivery.

Progressive Concepts of Electronic Record Systems

The basic concept of storing electronically the information held in a paper record, so that it may be available virtually in more than one place concurrently, will not be physically lost and may be processed to give added value such as scheduling follow-up appointments, has existed in live practice for some 50 years, and in that isolated and static format is indeed an outmoded concept. More recent technologies have made great progress by enabling radiological pictures, diagnostic tests and genomic sequences to be recorded directly in digital form, and held in a repository available in real time to all with a legitimate interest, while analyses, alerts, decision support and control, and controlled inter-linkage are now key elements. The challenges become not those of technology, but those of referencing and identification, of access control rules and governance, and of custodianship and reimbursement.

Secondly, care is delivered locally, by teams and individuals working within organisations that provide an operational environment. Such professional and support workers need to integrate the information profile (or record) of the client as related to the current intervention task with organisational information such as their own time availability and skill capacity, and that of others on whom they might call for complementary action, linked also to resource constraints and authorisation – a concept raised some time ago but yet to be widely adopted because of the complexities of organisational change and collaboration (Rigby and Robins, 1996). This thus involves several information systems, many of them dynamic. One single cross-organisational system would be unwieldy, and in commerce has been found to fail – instead a system of inter-relating specialist systems is needed, and rightly in this respect the European Commission and other interests are calling for system inter-operability.

Consequently the vision must move from electronic records for individuals to authorised access to inter-communicating record systems, which together give all the necessary information needed by a specified user for a specified purpose and context at a specified time regarding the individual. The research needed to progress this is not into technology (though developments in systems such as intelligent brokers is important), but into the issues of standardisation, terminologies, person and practitioner identification, indexing and governance, coupled with related studies of usability, intuitiveness, and education and training of users and of data subjects – the people-based issues. Crucially, requests and mandates must be clearly defined in relation to expectations, the degree of delegation, and the nature, timing and notification of report-back and hand-back (Consorti *et al*, 2000).

Remote Monitoring and Smart Sensing

A quite distinct set of technologies applicable in health and related care if applied soundly is the suite of methods of sensing. Vital physiological signs such as blood pressure and pulse rate can be monitored by remote sensor, either by the patient applying a sensor, by sensors under a bed sheet, or from intelligent fabrics in what is referred to as ‘mobile health’ or ‘m-health’. For instance, wearable sensors can indicate a change in heart rhythm indicative of an impending heart attack.

Some forms of hospital bedside monitoring can now be carried out by bedside machine in the patient’s home, linked by appropriate communications to a clinical base station. In turn, for some patients this can enable shorter stays in hospital with consequent quality and economic benefits.

Sensing or monitoring of activities of daily living, such as flushing a toilet, boiling water with a kettle, or opening a door at night, can monitor a person’s functional wellbeing. Unexpected cessation of activity, or unusual patterns of activity, can indicate that a person has fallen or is unwell, and can trigger a call for help. This is the application domain of Ambient Assisted Living, and is a field of overlap of interest between housing, social care and health services. The barrier to greater use is the need to devise acceptable and sustainable forms of service reaction, particularly where identification and need cross service boundaries, and availability of responses to home settings for other than ambulance attendance for acute life-threatening emergencies is often a challenge.

Further, for m-health to be effective with wearable devices, inter-operability needs to have new dimensions. The heart patient wearing a monitor needs to be able to travel outside his own town, otherwise the monitor is as restricting as an offender tag. But travel elsewhere in the country of residence needs universal related service responses as well as geographical location identification of the person and access to the lead health provider’s records, while travel to another country requires new forms of service inter-operability. The technologies can enable, but the service responses (including record access, language, financing and accountability) are the barriers to achieving the full benefits.

Looking forward, single aspect monitoring will be seen to be restricted. In the first instance, setting of alert levels, or algorithms to detect multi-aspect pattern changes within one field such as cardiac monitoring, is achievable, but each of these fields sends alerts back to specialist units. The potential to develop multi-aspect algorithms, so that modest changes within a number of different monitoring channels may be aggregated to show an overall more significant change, will require coming together of experts from different domains, such as clinical monitoring and housing-based daily living monitoring. Moreover, the potential to make such alert levels person-specific, as can apply with clinical monitoring, needs research that will also bring in potential citizen users as partners, yet at the same time needs to develop related structures of shared accountability.

Advent of New Technologies

New technologies will constantly come to the fore. These can be seen as falling into two categories.

One group is the new products and discrete microsystems that are devised containing considerable processing power. Examples are smart phones and downloadable applications (‘apps’) which can reside on a smart phone or on a personal computer. Already many are appearing in the health domain and are developing ahead of any organisational response about validation, licensing, or regulation – even though many are in effect medical devices. Rather like gunpowder, these can have considerable beneficial value if each is validated, proven, and applied appropriately, but the same technologies can be used recklessly and unreliably in a way which cause damage, or indeed to exploit the vulnerable. Other innovations include speech recognition for data entry, use of the domestic television as an interface, and closed loop voice-over-internet protocols

(VOIP) communication using traditional personal computers and broadband communication. Here the research issues are as much about user acceptability and integrity of data entry, output, and use, in normal settings outside the research environment. To paraphrase Evbuomwan (1996) at the end of the last century, design should be based on the process of establishing requirements based on human needs, transforming them into performance specification and functions, which are then mapped and converted (subject to constraints) into design solutions (using creativity, scientific principles and technological knowledge) that can be economically manufactured and produced. In other words the process should be social science led and then achieved by responsive technology solutions – so called ‘socio-technical design’.

The second group relates to internet sites and social networking. Here again the potential power to create extremely valuable benefits exists, but so does the opportunity of the unscrupulous to cause harm. Social networking and similar sites have developed new paradigms of support, as with various disease-sufferers sites, new forms of publication of institutional quality assessment, and legitimate campaigning sites, and new forms of open market service delivery have emerged. It is part of the power and vibrancy of the internet that new innovations outside traditional structures and restrictions can start, but that this freedom and innovation can be misused too, and can mislead. Society in general is too willing to accept the goodwill of those who develop new systems, and too reluctant to recognise that wrongdoers will exploit every opportunity as already happens with on-line financial fraud, false friendship requests, and paedophilic grooming. Science should be used responsibly, and part of the execution of that responsibility must be to identify from the outset the potential abuses as well as the beneficial uses, and to initiate the identification of controls against such abuses.

Hence governments and regulatory bodies need to research and develop new lines of response and of enabling regulation relating to health and social care information sites. This is potentially a grey area prone to passing of responsibility, and of not acting until problems occur. It is a cross-over area between health, social care, consumer protection, telecommunications regulation, and crime and fraud detection and of course it knows no political or national boundaries. Social science researchers need to join with technologists and regulators to ensure that this new world is protected from abuse without being constrained inappropriately. At the same time study should lead to new knowledge for

formal service provision through learning from the way such social media platforms are used and how consumers prefer to communicate, discuss and, most importantly, negotiate health and social care issues.

Application of Business System Logic

Many areas of commerce make heavy use of business systems to maximise efficiency, safety and customer satisfaction, and these are not solely dependent on leading edge technologies. Airlines and railway systems integrate many complex and rule-based systems of scheduling crew categories, equipment, time slots and passengers to create a seamless customer experience while running to good business principles. Retail chains match fluctuating demand to delivery and indeed production to optimise availability matching fluctuating demand. By contrast health systems are only just beginning to use applications such as theatre scheduling, while in general electronic systems automate traditional constructs such as waiting lists and referral messages, rather than making a forward appointment based on comparative urgency for other services particularly domiciliary ones such as home nursing and day hospital attendance with linked transport. And at this level integrating the schedule of health and care interventions for the individual patient is almost unheard of – yet in a modern information-based society it is surely not unreasonable for the citizen to expect the care for her arthritis and diabetes to be as coordinated and integrated as her package holiday. And with this should come also built-in systems of delivery monitoring, quality assurance, skills optimisation and an element of personal choice as to care pattern and feedback as to holiday or visit plans necessitating rescheduling (Rigby and Robins, 1996; Rigby, 2008). There is much social science research to be done to deliver this perfectly achievable position of efficient care for European citizens.

Record Access, Ownership, Custodianship and Responsibility



A specific issue which can get in the way of meaningful debate about shared and integrated care is that of record ownership. It needs resolving authoritatively, based on sound principles and related enforceable governance, supported by appropriate social research. Past patriarchal attitudes have included the claim that the health professional owned health records, while some hospital organisations claimed that the owner of the paper was the owner of the information on it – attitudes which acknowledged no autonomy of the patient, nor ascribed value to data. Conversely, in general the patient is not in a position to hold a large integrated record, on any medium. But unlike many records protected by data protection principles, there are shared and conjoint interests in both clinical and care records. Viewed in the obvious way, the data are about the patient, and so the individual citizen as data subject has a vital interest – but with the challenge that as a lay person the citizen may not be able to interpret the record fully nor update it. At the same time, viewed in another way the clinician or the social worker has a vital interest as each person-based record holds a crucial record of their decisions, actions and the subsequent outcomes. And for care giving institutions the composite of the data in the records holds the fundamental account of the organisation's actions and achievements, as well as being the source of funding and billing data. So there is co-dependence, based on mutual trust of the integrity of the record being that which was initially created in the process of practice, and never modified in any way.

In 1997 in the challenging context of considering electronic patient records in mental health (where some data subjects might not always be in a position

to give informed consent over data recording or use), the then Data Protection Commissioner for Ireland made the clarifying observation that the core principle was not ownership but trusteeship – that the organisation provides a data recording facility for all interested parties; that access to those records was a privilege of the data subject according to the view to be taken and the purpose of access; and that the organisation's duty was to ensure sound governance, including special protections for data subjects currently not able to exercise their own prerogative (Glavey, cited in Draper and Rigby, 1997).

That principle of duty of record trusteeship or custodianship holds strong benefits, but needs further consideration when different sources of data are brought together, for instance as discussed above in remote monitoring. Who then has custodianship and duty of care? And how does that extend when value-added processed data, such as an alert, are passed to a professional or organisation who has a care responsibility but has not requested the communication?

The extension to social care is further challenging. Here there may well be more than one data subject, as an assessment about the client is likely to be accompanied by assessments about the effects on, and responses of, other family members or informal carers. There may also be a need for shared care plans – perhaps where services are being provided jointly to an elderly couple, or a young disabled adult is being supported to act as carer for a parent, while in many other cases there should be a recognised element of 'caring for the carer', the nature of which will be related to both individuals' changing needs. Custodianship of the record continues to

hold as a core principle, but issues of record access and conflict in data subject views and interests need further consideration.

Finally, bringing together health, social care, housing and other data such as those of voluntary service providers, further compounds the situation. But at the core remains the simple objective – providing seamless integrated support to the individual citizen according to the citizen’s informed wishes. Professional or organisational vested interests can be more powerfully articulated, so social science research is needed to find solutions that the citizen can support and which promote overall societal interest in an enforced rights and governance context.

The Necessary Social Science Research Agenda for ICT Application



The previous sections have highlighted the demographic and economic challenges facing modern European society, and the issues in providing modern and efficient integrated services to the citizen. This relates particularly to the elderly and those with ongoing health problems that require cross-sectoral support to maintain personal health, but also applies to younger persons with on-going health or ability challenges, or following illness or accident. The next sections, based largely on the ESF-funded Exploratory Workshop (Rigby, 2010), define further the necessary social science research agenda regarding the development of harmonised informatics systems as the key to holistic shared support.

Citizen Centricity

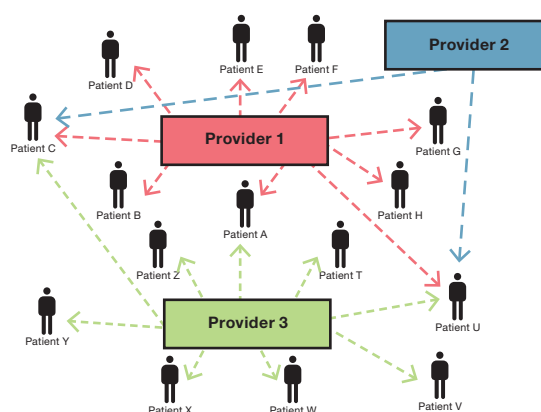
Effective health and care delivery must by definition focus on the individual – whereas historically it has focused on the provider's service to the individual. Modern technology enables data to be marshalled into new 'views' (Hägglund *et al*, 2007). But to achieve this, a series of practical and attitudinal issues need to be addressed, and the results turned into principles and policies.

Client Identity:

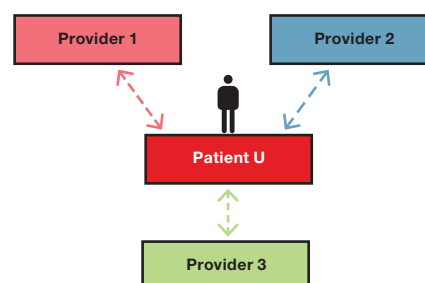
There are different ways of identifying citizens, including national identification numbers (as used for all services in the Nordic countries); national health numbers used for health care only and intentionally not linked to other services (as in the United Kingdom); and other local numbering including insurance client number and hospital and health

From Organisation Centric to Citizen Centric

A provider based picture...



... can be re-presented as citizen-centric...



... if the data are held electronically.

Figure 4. Refocusing on the Citizen

provider autonomous numbering. These systems are based on conflicting philosophies as well as on different traditions, and means of being able to identify the individual uniquely across different services, and indeed across national boundaries with European right to travel, and cross-border health system inter-operability to support cross-border care, need to be developed to enable care integration, yet at the same time must build on trust.

Professional Provider Identity:

To achieve integrated care delivery, each contributor must be able to identify and if necessary contact concurrent and previous contributors – organisations and individuals. Whilst for registered professionals each country has its own registration and identification system, these can be constructed and operate to different structures. Even more significantly, not all contributors are subject to formal regulation and recognition in all countries, whether organisations (residential homes, community care companies) or individuals (nursing assistants, social care staff) – each country has its own range of systems and gaps. Given the European Commission's commitment to skills identification and transfer and labour transferability, as well as the effective use of information systems to coordinate care, development of wider yet harmonised provider identification is an important necessary step forward.

Informal Carer Identification and Linkage:

As already indicated, citizens in need of health and related care support cannot be considered in isolation – their family and their own other caring commitments impact on their needs (both positively and negatively), while informal carers within and outside the family can need support and to be included in elements of the trusted circle of the virtual care team for the individual. Means of unique identification of these individuals becomes important, but currently is difficult in countries other than those with citizen identification numbers, while in the balance of countries there is often philosophical opposition to such identification, on grounds of personal freedom.

Secondly, these contributors to care, and persons affected by the citizen's own need, require means of linkage to the client so they can be identified as virtual care team members, kept informed of changes, and be given the opportunity of offering their own feedback. In principle such linkage systems are possible within information science (such as Google+ 'clusters'), but in a health and care context ensuring acceptability and practicality are very distinct but essential preliminary steps. Yet without tackling

and overcoming these social and attitudinal challenges systematically and scientifically, the virtual care team cannot be identified as such, and thus cannot be informed or fully effective.

Constructs of Privacy:

Confidentiality and privacy lie firmly at the centre of health and care practice and systems, and cover both private views and decisions, and personal history. As soon as an individual chooses to interact with others, they have entered into the public arena in that respect, but they still have autonomy in how much of their private sphere they reveal. In the provision of health and social care there are frequently grounds for the professional agent seeking maximum information within an envelope of confidentiality, but the client may not wish to reveal everything of their past (or present), though they should be counselled on the risks if they hold back relevant facts. How much an informal carer needs to know is even less clear cut, and conversely how much is recorded about a third party such as an unhelpful family member who aggravates the client's situation, and their third party rights, are difficult areas. What is clear is that the absolutes of total secrecy, and of open access to all interacting agents, are both unacceptable. Further research and the development of new guidelines are essential.

Autonomy, Access, and Ethics:

Comprehensive integration of data about and in the interests of the citizen can be very reassuring: when embarking on a plane journey or entering hospital for an operation citizens fully expect all

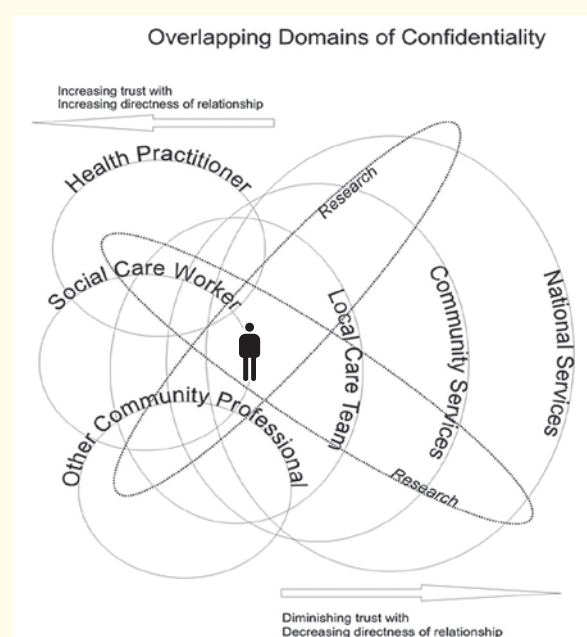


Figure 5. Domains of Confidentiality

contributors to be fully briefed about their needs and expectations, even though they will never meet or know the majority of these contributors. However, the thought of the equivalent marshalling of data about their personal support at home will produce in some citizens similar reassurance and expectation, while for others it will seem highly intrusive and controlling and thus may be rejected, even though constructed for their wellbeing.

Research is therefore needed on how to make such systems welcomed and accepted, particularly for older or less digitally literate and trusting citizens, and much will depend on interface constructs and client control and choice mechanisms. This needs to lead to development of intuitive yet effective systems such as client agreement of who is in their informal care team, structured levels of information sharing, and client-determined differential access control algorithms, which, in turn, need to be backed up by the development of governance systems and related audit and sanctions. There must also be monitored mechanisms for dealing with temporary, and enduring, loss of full mental competence, and with conflicts of view between different involved parties.

The Declaration signed by delegates to the ESF Exploratory Workshop, and which was reproduced by the OECD in the documentation supporting their joint workshop with the US National Science Foundation on Smarter Health (www.oecd.org/sti/smarterhealth), called for the drafting of a **Charter of Subject Rights for Electronic Record and Care Delivery Systems Containing Social Care Data**, recognising the rights

- of subject access not just to recorded historic data but also including access to dynamic data such as forward schedules;
- to express and record their own views and preferences;
- to record observations on their own health, functioning, and needs;
- to decide personal directions on individualised rules for information sharing to formal and informal third parties involved in care or family support;
- and explicitly qualified rights of defined appointed representatives and agents.

This unmet need seems no less strong now in order to make integrated information systems centred on personal health and care data acceptable and feasible, and should be addressed. Indeed, it echoes a previous Opinion of the European Group on Ethics in Science and New Technologies to the European Commission on the need for a European Patient's

Charter covering ethical issues raised by ICT in healthcare (Wagner, 1999), only this still overdue action now needs extending to cover coordination of health and social care delivery. The process of developing this should now also accommodate the issues of mental competence, and trusted third party advocating for those citizens not fully comprehending the issues and the potential benefits.

Acceptability of the New ICTs

To be effective as vehicles of service delivery, informatics systems in health and social care must be understandable and acceptable to citizens, both intrinsically and as implemented in systems and within policies and governance. Further, it must be emphasised that citizens are not homogenous – attitudes to information technology vary tremendously from digitally literate ‘silver surfers’ and those who use social media to keep in touch with family and friends, to those who are totally distrusting and frightened of digital technology. Whilst this heterogeneity is not a problem when use of ICTs is optional, it is a very different situation when digital systems are used as the means of delivering health and related care systems, where principles of equity and citizen acceptance must predominate. Indeed, a paradox emerges since those with greatest need though ill-health or frailty may well be those least digitally fluent or with minimal access to digital technology.

Avoiding New Inequalities:

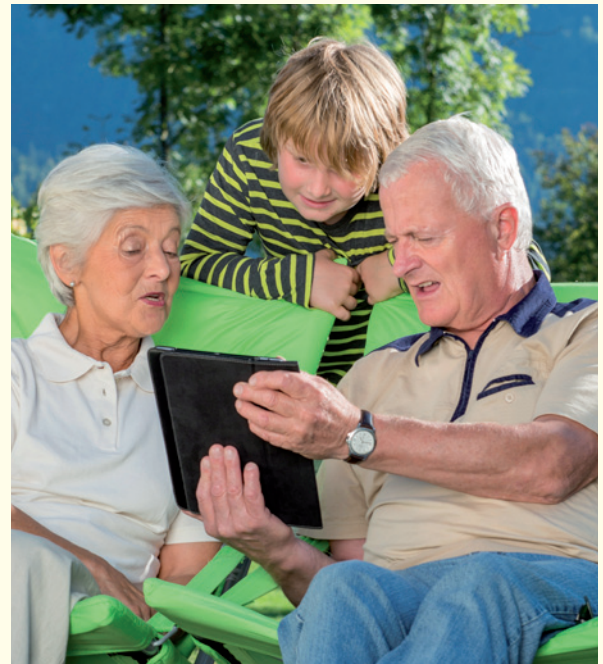
Health inequality is a recognised core issue, both through inequalities in exposure to adverse health determinants and in access to health services. Across Europe considerable efforts have been made to identify health inequalities and to address them, with considerable degrees of success. But as ICTs are brought into health and care delivery there is a high potential likelihood of creating new inequalities as digital understanding and access are uneven. This is partly based on education, income, and attitudes to technology. But there are other insidious inequalities, such as broadband availability – with more isolated rural residents more likely to have unreliable or absent broadband even though they are the ones most susceptible to physical isolation and difficulty in accessing services. Policy research and service access monitoring must constantly search for the onset of such new inequalities and find means of rectifying them.

Acceptability of Technology:

New technologies will have different degrees of acceptability, both between different citizens and between different technologies. Even systems such as computerised telephone response systems have been introduced with little thought on their disadvantaging effects on those with hearing impairments, those whose thinking is starting to slow down, or those who are not sure how to define their problem and wish to speak to an individual – even telephoning a provider organisation to change an appointment can prove impossibly difficult. More innovative ICT care systems will for some raise even greater barriers – for instance, while one at-risk citizen may find remote monitoring very reassuring, another with similar needs may find it unacceptably intrusive. Some may find on-line grocery shopping a great assistance, while others may find it increases social isolation and thus far less satisfactory than transport assistance to a supermarket. One client may happily use a screen-based system to describe symptoms or to reschedule care to fit round a social commitment, while another may not even understand how to switch on a computer-based system. Those support systems which have been proven on a pilot scale have usually been validated in selected research populations, on a voluntary basis and with exclusion of those with compounding factors. There needs to be further research on achieving widespread acceptability, while acceptability and feasibility studies need to be rolled out from pilot sites to beta sites with no special support and applied to all clients. And whenever a new service concept is introduced, there should be scientific study of its potential negative or perverse effects on some or all clients, and where necessary adjustment or complementation made.

Agents and Enablement:

One potential solution other than innovative interfaces is to develop a system of informed and trusted agents who can provide a human interface for the client in need. These may be family members such as grandchildren who are technology literate, trusted friends or neighbours, or where necessary persons employed for this role. This raises issues of appointment, verification of their input, and identification of them as individuals, if it is to be safe and effective. Other enablements to achieve effective equity of access also need further study and development, such as secondary schools providing ICT skills tuition, or day centres providing supported access facility.



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Benefits, Risks and Controls:

The effect of these issues is to heighten the importance of Health Technology Assessment (HTA) to cover not just the success of a new technology or application in achieving its core tasks, but the effects on and acceptability to citizen users and the responsible professionals, the identification of potential new or heightened risks, and the identification of appropriate controls are essential. HTA processes should make evidence available to inform decisions concerning adoption of an application, but can facilitate consideration of sustainability and transferability in addition to more obvious aspects such as success of technology or impact in clinical outcomes. HTA initiatives in Europe, in particular the EUnetHTA joint action (<http://www.eunetha.eu/>), are starting to address this need, but it is methodological work in progress, and its application is far from the common policy practice which it should be, and is usually application-specific. However, the global HTAi conference hosted in Bilbao in 2012 took as its theme *HTA in Integrated Care for a Patient Centered System* – an encouraging first step.

Key HTA Aspects

Policy/societal view

Systematic critical review including meta-analysis

- Clinical effectiveness
- Cost effectiveness
- Appropriateness
- Safety
- Acceptability

Produces policies to aid practice.

Virtual Team Partnership

As has been indicated, effective and efficient support for health for vulnerable citizens requires collaboration between formal services, and the involvement of informal carers, into a person-based virtual care team with central objectives but specific individual roles. But to be effective and reliable, new understandings are necessary.

Sharing Objective:

Putting the citizen at the centre is the shared concern of all the virtual team – the citizen is their subject of care. This should focus on the needs of the citizen at the centre of the health-care-societal circle rather than their physical entity, so as to encompass the notion of the patient as a co-producing actor, as represented in Figure 6. This also indicates their leverage on the other actors, together with the impact on the needs of other carers.

It is also important that all parties understand the core objectives of the care for the individual – it may be to enable a further number of years of independent living, or it may be more specific such as to ensure appropriate nutrition for a form of diabetes, or support at time of significant mood swings. If the virtual care team are not working in synchronisation their effects will be dissipated and inefficient; if they are working to clashing objectives the client will be confused and the support delivery inefficient (Rigby and Robins, 1996). Finding means of expressing such shared objectives, conveying them, and updating for changes needs further study.

Subject Respect and Autonomy:

While the core purpose of the coordination of care, and the empowerment of the virtual team, is to support the individual, this is in order to support a person who is an autonomous citizen with his or her own rights to lifestyle and choice – unless and until his or her mental competence is shown to be impaired. Therefore the person who is the subject of supportive care must have a central role in determining the objectives of that care, and within the bounds of resources and feasibility should have a clear voice in determining means and schedules. The views of core informal carers, especially where they have a physically continuous responsibility, should also be accommodated. Means of recording these client and core carer choices and preferences should be clear, transparent and shared as appropriate – and to do this new innovations in recording, display and practical respect need development.

Roles and Responsibilities:

Part of this shared support approach will be to confirm roles and responsibilities; this applies both to professional support (which professional will lead on which aspect and which others will support that aspect), and to informal carers (where commitments may be at the task level, such as collecting shopping or providing a hot meal, as well as more involved support). Key issues for the shared support record will be description of these tasks and their schedule, and notification of variation for any reason, so that health and care support is informally but reliably interwoven to provide reliable and seamless assis-

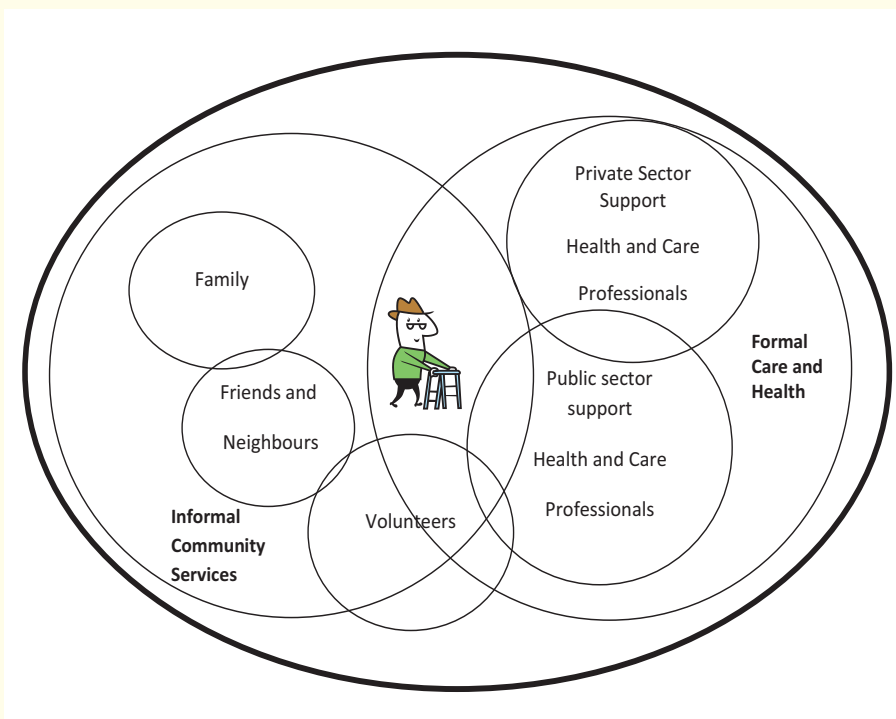


Figure 6.
Citizen-Centric Virtual
Care Team

tance – as has already been identified as necessary within the health sector (Consorti *et al*, 2000).

Skills and Competencies:

Similarly there needs to be better understanding and recording of skills and competencies needed for particular tasks, both formal and informal. Some support may need specific professional skills, so substitution of carer will need someone with similar skills; some may be simple but informed, such as ensuring that an informal carer can administer an insulin injection; and some may be daily living skills but also essential, such as whether a spouse can cook a hot meal. In system terms much still needs to be done to ensure recording of these aspects so as to ensure seamless and reliable support making best use of informal community resources where these are offered.

Respecting and Understanding Informal Carers:

Informal carers, in particular immediate family members, or neighbours, may find that provision of support to a challenged citizen is demanding, and their ‘hours on duty’ are considerable, while ‘going off duty’ is a luxury seldom achieved. Even being physically available to react to a fall, or toileting assistance, can reduce employment, socialisation or leisure opportunities. As the number of older persons and these with a managed chronic disease increases rapidly in society, so the need to ensure that informal carers do not become overburdened, or ill themselves, increases in importance. Thus support for and respect of the autonomy of these informal carers who are partners in the virtual support team becomes essential, on both practical and ethical grounds. These carers have been described by Kittay (1999) as ‘dependency workers’ – they support someone who is dependent upon them, but this dependency in turn makes them vulnerable, and thus in need of ‘care for the carer’.

Formal agencies, and related records, need to develop ways of identifying the needs of such informal carers for respect, support and indeed an allocated amount of guaranteed support in recognition of their own needs, creating a ‘carer-friendly’ regime. The concept of the informal carer as a resource, a team member, but also a person with consequent needs and rights in their own respect, is unfortunately currently seen as novel and little addressed – a need which should be remedied; this may also be cumulative across a number of caring responsibilities, for instance a healthy adult simultaneously looking after both children and aged adults, raising new challenges of cumulative responsibility

identification. Professional agencies, systems and financing should also adopt a ‘carer-friendly’ philosophy.

Common Language:

Finally, as the combination of support and information in the virtual support team is seen as important, so too are means of clear communication. Professional terminologies often do not cross well between professional domains; lay carers often use significantly different vernacular terms. Development of effective shared communications, including shared terms, is essential for understanding and safety.

New Paradigms of Care Delivery

Apart from new means of sharing care responsibility, including accountability and funding, round the individual, new paradigms of care delivery enabled and supported by modern informatics are needed. Benefits to be striven for should ensure better quality of service (potentially at similar or lower volumes of input), greater reliability and better accommodation of preference and choice (in turn achieving less waste of resources). The component technologies and systems are not new, though their application in the health and social care fields may be so, and new intuitive and user-friendly interfaces are needed. Key elements, that need to be developed on a research base, are outlined below.

Time Management:

Automated systems should enable creation of multi-view patient diaries; professional time resource management; better management of facility resources such as day care places; journey scheduling for staff and transport scheduling for patients; and technology assisted referral and support scheduling, request handling, and available solution negotiation.

Delivery Monitoring:

Monitoring of delivery in near real time would identify potential service gaps, such as when a nurse is delayed by a crisis with one patient and thus risks compromising the commitments to other patients, enabling notifications to be sent or – in important time-critical cases – an alternative provider to attend. Such systems could also facilitate other urgent messaging, such as when a client is unexpectedly absent, or a care provider is ill or has a transport breakdown.



Synchronous Scheduling Modalities:

In a consumer-oriented service, clients should be notified of an anticipated appointment time for domiciliary visits (or of transport arrival times for attendance elsewhere), rather than simply being asked to wait for an arrival. But conversely, such systems should enable client feedback, so that clashes can be avoided and thus resources not wasted. It is not the technologies so much as the approaches and systems which are currently lacking.

User Messaging:

Similarly, integration of user messaging into scheduling systems would enable clients to advise in advance any queries, worries, or changes they perceive in their situation, so that professional carers can be prepared to address those issues, both in terms of information and expertise, and in time preparedness.

Planning Tools:

Other service fields make use of automated planning tools, linking in to resource availability and driven by agreed rules. Development of such systems in health and care interlinked would enable citizens as well as formal carers to build packages of care related to personal need, practical resource limits, and policy constraints.

Assessment and Decision Support Tools:

It is one thing (both for citizens and professionals) to identify risks, needs and self-care limitations, but it is another to consider service solutions, especially when different interactions or complementary packages of care input could be considered, and to make a final shared decision and ensure its delivery. Development of decision-making tools would be of benefit, not least as they could enable citizens and their informal carers to consider alternatives prior to discussion with formal providers. New concepts of user-friendly intuitive devices utilising technologies such as touch screen and drag-and-drop could be developed for this field.

Interfacing with the Care Knowledge Stores:

In some initiatives, giving citizens better information about service types (and their relationship to specific support needs) is being addressed; issues include trusted and authenticated data stores with representation of service type, providers and availability in social and related care, especially in local mixed markets and where external payment and user payment may both apply. This is important but in an information-based society should go further – for instance, knowledge management services could help inform citizens' and carers' choices.

Responses to Monitoring and Third Party Feedback:

Response to remote monitoring alerts needs further research which crosses organisation and system boundaries. For instance, a housing service may staff the monitors, but it may be a health crisis which appears to have occurred. In turn, ambulance services may only be willing to respond to advanced clinical crises, while duty social workers and home care nurses may not provide 24 hour coverage and may not be authorised to attend unknown situations single-handed. In short, the technology can provide the monitoring, but it needs the development of a new pattern of service, person-centric and crossing old boundaries of service demarcation, to provide an effective and efficient service response.

A similar situation arises with feedback from third parties within a holistic service pattern. For instance, if a carer supplying a hot meal feels that the client's mental state is becoming confused, or if the person cleaning the house feels that the temperature is getting too low and the heating is not working, they themselves cannot provide an immediate response, but should be able to feed into the integrated care team an alert which is reliably picked up and acted on by the relevant person – either a specialist or a lead worker. But some changing needs will only be evident from an overall analysis of feedback, when a number of small changes observed by different carers or metrics add up to a more significant picture. The development of truly holistic views and responses needs sensitive and informed further study.

Data, their Controlled Sharing and their Protection

Data are vital to health and social care delivery. They include items that are traditionally seen as the contents of a health or care record, but they also include digitised images and other diagnostic data;

process data such as referral requests and scheduling data; clinical guidelines; telemedicine and telecare records; and monitoring data together with any derived analyses and alerts.

Charter of Subject Rights for Electronic Record and Care Delivery Systems Containing Social Care Data:

Reference has been made earlier in this document to the need for this, and its content should be based on research into views of acceptability for citizens and professionals.

New Paradigms of Data Custodianship:

In a complex multi-provider setting, assessment is needed of the best models of custodianship of citizen related records that need to be accessed, on a controlled client need basis, by other providers. The construct, legal mandate, resourcing, governance and audit need careful consideration, in order to ensure trust by all parties, as well as efficiency and reliability.



Trusted Record Access Models:

In the need to balance confidentiality with safety and seamlessness of service, more sophisticated models of segmented or layered access controls need to be developed. This may include differential access for members of delivery teams within one

provider setting, and function-based communities of interest crossing the boundaries of contributing organisations. Role-based and profession-based approaches give a valuable base-line, but common real-world issues such as dual and temporary roles, staff substitution, training placements and locum cover need to be included, as well as quality assurance and audit functions.

Client Record Access:

Hitherto records have been held by health and care organisations, and only in very specific fields such as a maternity, and parent-held records for infants, have patients held medical records. Apart from tradition, two factors have been strong in this – safety of the single entity paper record and patient understanding. However, with electronic records, better societal education and availability of on-line and library information, matched to recognition of citizen ownership of their health and co-ownership of their treatment, such restrictions are increasingly considered outmoded. Innovations are now in place in several countries for citizens to have access to their own electronic health records, and indeed this is now formally encouraged by European Commission. However, this innovation has not yet addressed the challenges of cross-agency care, particularly with social care, where there may be reasons for withholding some of the record content, not least to protect third parties. Serious ethical issues are raised in this, not least where conflicting interests and views arise, indeed within a family. These issues and principles should be considered and discussed publically in a structured way.

Citizen-based Differential Access Control:

Whatever models are developed, final authorisation for setting access levels must lie with the citizen, who should be able to give protection to specific parts of their record, and to be able to give identified individuals, or functional groups, specific levels of access. For simplicity, this may well be based on a default model, but the options should be easy to apply. Further, means of citizens nominating a named trusted agent to exercise certain functions should be included.

Third Party Interests:

Though records are based on individual clients, the nature of health and care records creates three types of third party interest. First is the professional practitioner interest, since they are identified individuals whose actions and their consequent outcomes are primarily recorded in the client record. Second, and particularly in social care, there are identified family

members and other informal carers (as mentioned, genomics and personalised medicine may raise new aspects of family third party interest as well). Third, particularly in insurance-based systems and managed care contexts, the provider organisation has an interest in the care of the individual and how it is executed. Deeper consideration is needed to ensure that these considerable interests are met, while at the same time not compromising either core client confidentiality or societal trust; consequently, more explicit principles and procedures, exploiting modern information processing constructs, should be developed.

Mental Competence:

Nearly all settings recognise the competence of the individual to make their own informed decisions. For children and young persons, while all countries have their own statutory age of majority when the child becomes an adult, increasingly recognition is given to the fact that children have views and rights from an early age, and most countries adopt an approach of a gradual attainment of autonomy, based broadly on the ruling of Lord Scarman in the Gillick case in the United Kingdom in 1985 (Times Law Report, 1985).

However, with regard to adults, full mental competence is still assumed until proof of lack of mental competence due to mental illness or intellectual disability, at which point other systems come into action. This 'yes or no' defined hard boundary approach is unrealistic in the case of illness, frailty and ageing, where a citizen capable of managing their own daily living will be overwhelmed by more complex issues, and adopt arbitrary solutions when confronted with choices, especially where they involve unfamiliar technology. Concepts of restricted or partial competence need to be developed and defined, for instance recognising aspects of clear competent choice on lifestyle preferences while delegating to defined others finer details or other more difficult aspects. This needs to be matched with forms of recognition of authorised agent action, and means of recording this.

Data Contributions:

Not least for reasons of veracity and trust in accuracy, only professionals and employed carers traditionally have been able to make record entries – though some exceptions such as patient diaries and patient completion of assessment questions, have value in specific settings. With increasing empowerment, and health co-ownership, this is increasingly seen as unnecessarily paternalistic as well as inefficient. There can be value in clients and their informal car-

ers recording feelings, and functional changes, as well as vital sign self-monitoring, so as to inform the overall care process. Development of types of record adjunct, and criteria as to when the data should be included in the formal record, or the professional carer alerted to changes, need special study.

Information Construct and Representation

To make best use of information requires science-based means of its representation and presentation. Usability studies partly cover this, but other issues need study too.

Vocabularies, Terminologies, Taxonomies and Ontologies:

If information is to be meaningful and interpreted safely and unambiguously, more consideration needs to be given to the terms built up in different care areas and between providers and citizens. Vocabularies refer to the sets of terms used, and definitions can be attached. Taxonomies set terms into a structured, often hierarchical context of meaning. Ontologies are means of cross-linking different sets of terms. With the development of information science, vocabularies and terminologies are much more studied, but still remain specific to a professional area. Computing power gives opportunity to automate ontologies to cross-link terms, but the context-specific definitions and ground rules must be determined first. If workers from different health and care domains are to communicate safely, and if clients and informal carers are to interact with this, then much work needs to be done in developing these concepts.

Information Visualisation:

Words and scientific measurement values are indispensable. But often a graphic representation, particularly of changes over time, or of the exceeding of threshold values, can be very effective. Composite incorporation of sets of visual indicators into dashboards is gaining interest. Much more work needs to be done in the context of holistic integration of health and care support to yield visual indication of progress and of risk.

Context-based Search:

The amount of information is continuously growing and holistic healthcare includes very diverging types of information from different sources that need to be visualised for, and interacted with, by a variety of different users. Thus there is a necessity to identify

information and communication needs related to different contexts of use, and smart context-based search algorithms are needed to avoid information overload.

Organisational and Legislative Aspects

Health and Social Care Models:

Provision of health care and of social care are issues of national competence, not least in the European context. Though broadly two models exist – public funding or insurance-based funding – each country has its own variation, with matching legislation, regulation and funding. Different forms of co-payment exist, and of supporting those of low income and also children; in some countries legislation and regulation are at the regional or provincial level. The differences between the two broad models are now reducing as a number of countries introduce forms of managed competition within publicly funded services, but this yields many more variants. Perversely, the one commonality across nearly all countries is that health and social care are covered very differently within the country, causing major problems for coordination and the provision of holistic care. While national autonomy is not to be challenged, more study would indicate how best to operate each system and achieve citizen-based integration.



Inter-organisational Tension:

Whatever the system in place, an ever present issue is tension between providers caring for an individual citizen – both within care sectors and between sectors. Two forms of tension exist, and each in turn is exacerbated by principles of patient choice and of consumer selection of choices which are not the cheapest or easiest, but are still reasonable requests.

One tension is on finding common care objectives and means of providing support to this end. Each key agency may seek a different outcome or seek greater input from others. Client views are important but may not always predominate. There is need for much more work on means of creating the shared vision of the patient's planned progress and outcomes, of taking client views into account, and for recourse not least by the client to impartial moderation and review.

The second tension is pressures to transfer resource demand to partner providers. Even within publicly funded systems, budgetary pressures may make each contributor to care seek to transfer costs and care activities to others. And with differently funded care contributors, sharing physical resources or costs of individual care is difficult. Yet it is the dependent citizen and the informal carer who are frequently the victims of these organisational frictions.

A civilised society must find means of addressing these real issues. Though not initially an ICT issue, information systems cannot be designed and implemented unless there are clear rules to be included in their processes; conversely they can be designed as vehicles for the agreed solutions.

Governance and Quality Assurance

Integrated health and social care provision, especially when supported by ICT and delivered by a virtual team, generates two new sorts of governance challenge.

Managing a Mixed Market:

Mixed markets within service provision often provide regulatory challenges. Forms of accreditation, regulation and verification are needed at the level of the individual provider, but also at the level of the function of the market. There is a need to provide reassurance yet not to stifle innovation or the provision of niche services such as those providing services in a different language to meet minority needs. There needs to be a system for dealing impartially with complaints and queries both from other providers and from service recipients. Not only

do systems need to be designed, but also means of funding and sustaining them, whether as a public expense or from a provider levy, and in turn this will generate data requirements which should be built in, not retrospectively bolted on.



Quality Assurance and Audit:

Existing health and care systems have developed strong governance and audit systems, not least clinical audit and also complaint handling, to maintain quality standards and to protect the public. Virtual systems, shared care and cross-agency provision, together with informal care partnerships, while all highly desirable in a modern society, cut across these quality assurance mechanisms so carefully developed. Far less effort has gone into designing, verifying and setting as a norm new means of audit and quality assurance – both of the delivery of care components and of the individual client's cross-agency care programme. This is an unmet requirement that needs urgent study.

Integration into an Informed Supportive Society

Care delivery, including that which is ICT-enabled, is only part of the response to individual and societal need, and should supplement that which can be provided by families and by society.

Encouraging Voluntary Support in a Holistic Context:

There needs to be greater opportunity to encourage such socially responsible and productive volunteering and societal support, to specific individuals as friends and neighbours or more widely, by healthy older citizens as well as by younger volunteers. Indeed, this should be seen as a positive outcome and counterbalance within the issues of demographic ageing. However, the science of under-

standing volunteering is young and needs further development. But on top of research into the sociological and psychological aspects of motivation, perceived reward and triggers, and conversely the barriers and blockages, there is a deeper research agenda necessary. How to give the recipient as well as the volunteer choice, how to use volunteers to complement formal services but within defined levels of competency and responsibility, how to compensate for personnel and skills shortages but not replace needed employment or undermine legitimate businesses, how to create partnerships with formal services without inappropriate breaches of privacy, and how to ensure reliability and accountability, are some of the core issues – as well as how to instigate responsible systems which are not so intrusive as to negate the autonomy, flexibility and altruism of the act of volunteering, and how to record and use the relevant data acceptably and ethically.

Research is also needed into newer, stronger and more coordinated models of provision, without losing the power of voluntary action. But also, in the context of integrating support to individuals, the interface of such organisations with the professional personnel and record systems of formal services needs further study in the context of changing society – for instance, is a support function merely a request system with no delivery monitoring or outcome feedback, or should there be some very modest form of situation feedback?

Education, Training and Assurance

New technologies, especially intangible ones such as distributed data capture, processing and storage, create their own distrust and anxieties. Different citizens and professionals have different degrees of trust in the internet, or in remote reference sources or purchasing. More trust will be placed in a paper record written by an unknown person than in an electronic record, due to perceived lack of verification.

Authentication and Awareness:

Much more work needs to be undertaken in researching means of ensuring trust, and in accepting trustworthy systems. Two aspects are necessary – firstly into the creation of robust systems of verification, data integrity and system governance; and secondly into means of creating public and professional awareness in how to authenticate a trustworthy source. Widespread reporting of unfortunate and irresponsible loss or misuse of personal

data, outside health and care but unfortunately on occasions within it, has made this task unnecessarily difficult. Thus once effective governance frameworks have been established, with appropriate strong sanctions, means of creating public assurance and trust are vital. Civil aviation has achieved this position in recent years – few people can understand aeronautical technology but all trust it – but banking arguably has partially lost it.

These are key research and applications issues for the health and care sectors to consider actively, of which public as well as professional education is a key part. Wide-scale public education is an important final stage, including assurance of governance, product reliability based on criteria such as HTA assessment or CE marking, veracity of data entered by others in other locations, and application of education and training standards as discussed below to ensure safe use. The Chain of Trust project in the field of telehealth (www.chainoftrust.eu), led by the European Patients Forum and financially supported by the European Commission, is one encouraging innovation.

Health Literacy and e-Literacy:

If citizens are to self-care, and to make informed choices about lifestyle and formal care, they must understand health and its determinants as well as treatments, but they must also be educated both in health literacy and in e-literacy. On the latter, initiatives such as the e-citizen project of the European Computer Driving Licence Foundation (www.ecdl.org/programmes/index.jsp?p=2227&n=114) are a useful start, but much more work is needed to make such concepts universal, raising issues both of what is needed to be known, and how to achieve widespread population education. Health literacy concepts are being established, but then need to be bedded into e-literacy as a specific area of citizen activity.

Education:

If professionals from the health and care sectors are to be able to use electronic systems safely and effectively, they must be educated appropriately. Currently the great majority of professionals were educated based on paper system concepts; interacting with digital systems and virtual environments needs different approaches. Current initiatives to include informatics in basic professional education need to be made systematic, while the much bigger challenge of modular education for existing staff needs study and solutions. The Health Module of the European Computer Driving Licence (www.ecdl.org/programmes/index.jsp?p=108&n=764)

is one approach to practical education needing much more active application (Rigby *et al*, 2007), and has faced the difficulty of linking the computer education and health and care worlds, neither of which fully understands the other at national level. Barriers and solutions need to be researched.

Meanwhile, informatics staff with generic computer system skills need to become fluent in the needs of the health and care sectors and their special characteristics, starting with the development of curricula. Foundations exist in the work of the International Medical Informatics Association (Mantas *et al*, 2010), and national schemes, but the development of core competencies and qualifications would seem a common European need, and not to be left to the individuality of each university, training agency and employer.

Training:

Training in specific applications, including on-line and help-based solutions for citizen products, is important to achieve safe and effective use. Models and standards should be developed and validated with regard to common conventions and constructs such as icons and terms, and submitted as European standards. If these are research- and evidence-based they will be far more robust and are important for patient safety and citizen trust.

Financing Challenges

No services can be provided without money, and finance requires strict accounting rules. In integrated health and social care delivery four broad issues arise, all of which involve in different ways the ICT support.

Financing of the Care Systems:

As each care system has its own financing method, rules about costing and recharging, and where necessary of seeking and recording client co-payment, need building into the record systems. Pre-authorisation, both professional (as to appropriateness) and financial (as to reimbursement eligibility and any limitations) may well be necessary. Issues of rationing, prioritisation for use of funds and sustainability may arise.

Mixed Markets:

Frequently in social care, and increasingly in health, there is a choice of service providers. Cost is only one of the factors involved, with modality of care, availability, suitability and patient choice being others. Resolving these different aspects to give an

agreed financially supported package needs clear protocols which also support equity and reasonable choice.

Cross-Agency Integration of Care:

Where care providers should collaborate to provide integrated and holistic care to the individual, each contributor is dependent on the commitment and reliability of the others. Further, there can be tendencies to push costs onto partners, or suspicion that this might happen. Means of agreeing care packages at a care management level above and supportive of the professional carers is needed, as is being tried in the Netherlands.

ICT Support Infrastructure Policy and Costs:

Finally, and essential in this policy context, there need to be means of coordinating ICT policy and systems, and of providing those infrastructure systems (which may well involve patient records, or brokers systems to access enterprise systems) on which a number of agencies and providers are dependent to provide integrated health support. Many e-health systems fail or operate sub-optimally because financial benefits or user reimbursements do not accrue to the system provider organisation, and because there is no umbrella cross-sectoral agency. Models of cross-agency policy, funding and reimbursement are needed, including examination of public sector 'public good' funding, contracted third party provision to an agreed cross-agency or governmental commission, or cross-charging mechanisms (Rossi Mori *et al*, 2012; Stroetmann 2012; Stroetmann *et al*, 2011).

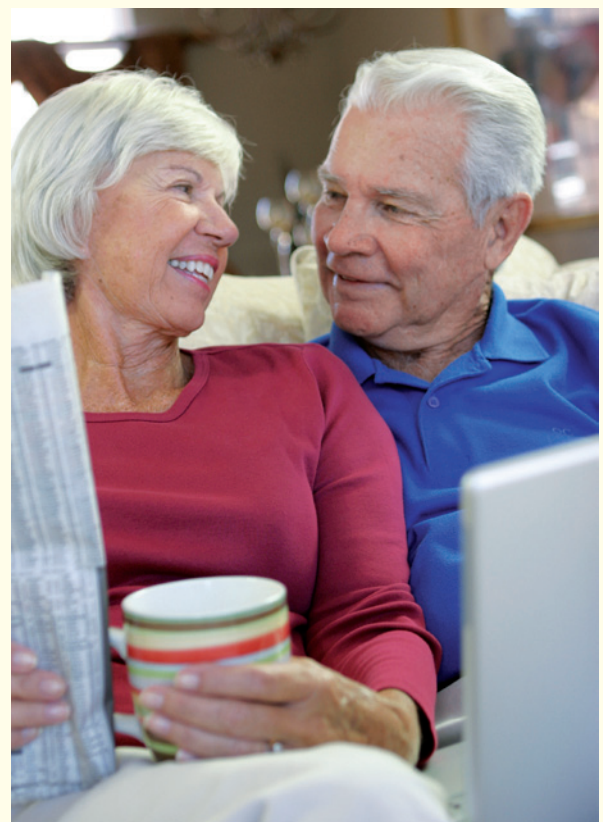
Conclusion



A growing section of European society with moderate chronic disease, frailty of older age, and lack of accessible family support, are at risk of compromised health. Modern European society has created many services to help these citizens. But these services are split into organisational clusters such as Health, Social Care, Housing, and others, each in most settings separately organised, delivered and recorded by organisations and their staff who are separately funded, managed, and regulated. As a result patients are surrounded by uncoordinated Islands of Excellence, when what is needed is Coordinated Care. This pattern is not sustainable economically or morally.

Information and communication technologies can help in many ways. Most of the technology already exists, but what is lacking is the necessary modernisation of records, virtual team building to empower family carers and harness social capital, organisational change in practice, and new governance and management processes. Current research is primarily into the technology within health care and ambient assisted living, and in spotlight pilot projects, with too little emphasis on citizen-centric integration and coordination, or assessment of acceptability. There is an outstanding requirement for research into the effects on equity, acceptability and effective roll-out from pilots to general use, and the production of convincing impartial evidence from validation and replication.

Given that European society is facing a major growth in the need for health-related support to its citizens, based on a changing demographic profile, greater health sector achievements in preserving life, and increased societal and consumer expectations of good service quality, there is a need to understand the new range of societal expectations using tech-



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nologies familiar in other sectors, balanced by new forms of accountability and governance. Future citizen health support should be holistic and integrated, personalised to the individual, rather than provided to standard packages from autonomous suppliers. Information science and ICTs can provide valuable means of ensuring this coordination, efficiency, sensitivity and specificity, yet on the whole though the technologies and techniques largely exist and are used in other sectors, there is much work to be done in applying these in a researched and evidence-based way in health and related care domains.

Finally, it must be emphasised that the central objective is the provision of supportive care to citizens in need, who are often frail and vulnerable, in ways which behave a modern caring society. ICTs and related organisational constructs can do much more to enable that support is delivered, and in an effective way, but use of ICTs themselves is not the objective, which is to ensure caring delivery of effective support for health for vulnerable and dependent citizens – the integration of a caring society and an information society to achieve Health for All.

This is an area where the social sciences should have a lead role. Research programmes need developing at national and European level to stimulate a comprehensive and cohesive pattern of social science research into the means of achieving optimal ICT support as the enabler for a new integrated and partnership paradigm of health-related care, appropriate for a responsible but demographically changing European society.

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Annexes

1. ESF Exploratory Workshop – 22-23 July 2010

The Challenges of Developing Social Care Informatics as an Essential Part of Holistic Health Care

List of Participants

Convenor:

- Michael Rigby
*School of Public Policy and Professional Practice
Keele University, United Kingdom*

Facilitators:

- Penny Hill
NHS Information Centre for Health and Social Care, Leeds, United Kingdom
- Debbie Keeling
Manchester Business School, Manchester, United Kingdom
- Sabine Koch
Health Informatics Centre, Department of Learning, Informatics, Management and Ethics (LIME), Karolinska Institute, Stockholm, Sweden

Participants:

- Albert Alonso
Fundació Clínic per a la Recerca Biomèdica, Barcelona, Spain
- Elske Ammenwerth
UMIT – University for Health Sciences, Medical Informatics and Technology, Hall in Tyrol, Austria
- Walter Atzori
European Patients' Forum, Brussels, Belgium
- Bernd Blobel
eHealth Competence Center, University of Regensburg, Medical Center, Regensburg, Germany
- Luca Buccoliero
Centre for Research on Health and Social Care Management (CERGAS), Università Bocconi, Milan, Italy
- Persephone Doupi
Information Division, National Institute for Health and Welfare, Helsinki, Finland
- Valgerdur Gunnarsdottir
Directorate of Health Policy and Health Services, Ministry of Health, Reykjavik, Iceland
- Jacob Hofdijk
European Federation for Medical Informatics, Oegstgeest, The Netherlands
- Hannele Hyppönen
Information Department, National Institute for Health and Welfare, Helsinki, Finland
- Els Maeckelberghe
Kropswolde, KvK Noord, The Netherlands
- John Mantas
Department of Nursing, University of Athens, Athens Greece

- Reli Mechtler
Department of Health System Research, University of Linz, Austria
- François Mennerat
Rix-Trébief, France
- George Mihalas
Department for Medical Informatics and Biophysics, Victor Babes University of Medicine and Pharmacy, Timisoara, Romania
- Sonja Müller
Empirica Gesellschaft für Kommunikations- und Technologieforschung mbH, Bonn, Germany
- Christian Nøhr
Department of Development and Planning, Aalborg University, Denmark
- Angelo Rossi Mori
eHealth Unit, Institute for Biomedical Technologies, Italian National Research Council, ITB-CNR, Rome, Italy
- Elizabeth Rynning
Department of Law, Uppsala University, Sweden
- Peter Wells
Cardiff School of Engineering, Cardiff University, United Kingdom

2. ESF Exploratory Workshop – 22-23 July 2010

The Challenges of Developing Social Care Informatics as an Essential Part of Holistic Health Care

Workshop Programme

Thursday 22 July 2010

9.00-9.30

Welcome by Convenor; Mutual Introductions
Professor Michael Rigby (Keele University, UK)

9.30-9.50

Presentation of the European Science Foundation (ESF)
Professor Bogdan Mach, Polish Academy of Sciences, Warsaw (ESF Standing Committee for the Social Sciences (SCSS)) (presented on his behalf)

9.50-11.00

1st Morning Session: Scene Setting

9.50-10.10

Introduction to the Topic and its Challenges
Michael Rigby (Keele University, UK)

10.10-10.35

Essentials of Social Care Service Delivery
Penny Hill (NHS Information Centre, Leeds, UK)

10.35-10.50

Collaboration in Health and Social Care Electronic Records
Sabine Koch (Karolinska Institute, SE)

10.50-11.00

Initial Questions
Coffee / Tea Break

11.20-12.45

2nd Morning Session:

The Current Situation in Europe

11.20-12.20

Overview of Awareness, Issues and Progress in Participants' Countries
Presentations and situation assessments from delegates

12.20-12.45

Generic Questions

12.45-14.00

Lunch

14.00-18.00

Afternoon Session: **Identifying the Issues**

14.00-14.15

1. Identifying the Individual: approaches to Citizen ID
Michael Rigby

14.15-14.30

2. Identifying the Family and Care Network
Penny Hill

14.30-14.45

3. The Privacy and Support Conundrum regarding Carers
Michael Rigby

14.45-15.00

4. Working to Budget Envelopes and Resource Constraints
Penny Hill

15.00-15.15

Coffee / tea break and *Workshop Sign-up*

15.15-15.30

5. Sharing Purpose and Mission in Care
Sabine Koch

15.30-15.45

6. Sharing Terms, Meaning and Language
Penny Hill

15.45-16.00

7. Empowerment and Communication
Michael Rigby

16.00-16.15

8. Attitudes to and Personal Input to Electronic Systems
Debbie Keeling

16.15-17.15

Parallel Workshops:

A. Supporting the Citizen and their Careers –
Michael Rigby

B. Understanding Terminology and Meaning –
Penny Hill

C. Who should See and Share Records? – Sabine Koch

17.15-18.00

Plenary Report-back – Agreements and Issues

18.00

Break

19.30

Workshop Dinner, Old Library, Keele Hall

2. ESF Exploratory Workshop – 22-23 July 2010

The Challenges of Developing Social Care Informatics as an Essential Part of Holistic Health Care

Friday 23 July 2010

9.00-12.45

Morning Session: *The Potential Role and Challenges of Electronic Shared Care Records*

9.00-09.20

Record Sharing – share, view, or broker?

Michael Rigby

9.20-09.40

Privacy, Permissions, and Protection

Debbie Keeling

9.40-10.00

Ownership, Authorship, and Authenticity

Penny Hill

10.00-10.20

Electronic Diaries

Michael Rigby

10.20-10.45

Coffee / Tea Break and Workshop Sign-up;

Vacate Rooms

10.45-11.45

Parallel Workshops:

C. Electronic Record Provision and Custodianship –

Michael Rigby

D. Electronic Record Content and Constraints –

Penny Hill

E. Electronic Record Linkages and Exchanges –

Sabine Koch

11.45-12.15

*Plenary Report-back – Rapports, Research Needs,
and Remaining Issues*

12.15-13.15

Lunch

13.15-14.00

**Afternoon Session:
*Action Planning – Parallel Discussion
and Consensus Sessions***

Parallel Workshops:

Technical Issues – Sabine Koch

Citizen Issues – Debbie Keeling

Professional Issues – Penny Hill

Organisational Issues – Michael Rigby

14.00-14.30

Report Back – Headlines

– *Principles*

– *The Research Agenda*

– *The Awareness-raising Agenda*

– *Locus and Ownership of Action*

14.30-16.00

*Concluding Action Plans for follow-up Research
and Collaborative Activities*

– *Outcome Statement*

– *Action Plan*

Social Care Informatics meets Health Care Informatics – a Holistic Citizen-Centric Vision for Information and Communication Technologies to Support Personal Health

The Members of this European Science Foundation Exploratory Workshop, held at Keele University, Staffordshire, United Kingdom

Recognising

- that Health is internationally defined as a state of physical, mental and social well-being and not merely the absence of disease;
- the essential nature of the Fundamental Human Right of every citizen to the highest attainable level of personal health;
- that to reach this maximum achievable state of health many European citizens require individual support with essential functions, which can include mobility, nutrition and feeding, personal hygiene, social and mental support and assistance with tasks of daily living, together with appropriate housing and financial stability;
- that whilst in an integrated society the prime sources of this support come naturally from family and community sources, nevertheless (and increasingly) many individuals need assistance from formal sources, predominantly social care services working in harmony with health services;
- that according to individual needs this support may be needed either to cover a short-term problem or may be needed sustainably in the longer term;
- that this health-enabling support should be provided with a philosophy of meaningful empowerment of the citizen, all having equal rights and individual expectations, as well as the right to respect for private life, with its implications for individual self-determination and other aspects of privacy;
- and believing that current and emergent Information and Communication Technologies can significantly facilitate the effective and individualised delivery of such services specific to personal needs and circumstances;

Declare the fundamental importance of

- providing harmonised health and social care services that meet the extended needs of the individual, taking into account diversity in need, preferences, ability and support; and also recognising the concurrent resultant rights and needs of informal carers as individual citizens;

- focussing these services on the individual citizen as the beneficiary, including the pattern of delivery they find most effective;
- and to this end, utilising modern Information and Communication Technologies as enabling services, as part of a wider health and social care toolkit;
- whilst recognising the importance of e-services being an appropriate enabling mechanism, and not an inappropriate replacement for necessary inter-personal interaction;
- and also recognising that citizens may move between European Union Member States (or indeed wider) during the period of need for support.

To this end, the Members of this European Science Foundation Exploratory Workshop **call on relevant authorities** to initiate and facilitate a programme of Research and Development to include:

- Drafting a Charter of Subject Rights for Electronic Record and Care Delivery Systems Containing Social Care Data, recognising the rights
 - of subject access not just to recorded historic data but also including access to dynamic data such as forward schedules;
 - to express and record their own views and preferences;
 - to record observations on their own health, functioning, and needs;
 - to decide personal directions on individualised rules for information sharing to formal and informal third parties involved in care or family support;
 - and explicitly qualified rights of defined appointed representatives and agents.
- Eliciting and defining the Range of User Needs for an ICT-enabled supporting framework, to provide different users and stakeholders with context-relevant knowledge based on citizen-centred health and social care information as well as coordination and communication.
- Defining a Community of Practice that shares knowledge, innovation and good practice, enabling future learning and further development of terms and meaning, including definitions of membership and responsibilities. This should include consideration of the different approaches of the health and

3. Declaration by Members of the ESF Exploratory Workshop on Social Care Informatics and Holistic Health Care, Keele University UK, July 2010

the social care domains, and the areas of overlap between aspects of community nursing and aspects of social care.

- Developing a shared Ontology and Meta-Taxonomies for Social Care linked also to Health Care that supports a range of core standards and terminologies to underpin need assessment, service planning (both short-term, and to meet lifelong needs), service provision, and the monitoring of outcomes, and that enables safe and consistent information sharing across social care, health and other sectors around the citizen. Ensuring that this ontology relates appropriately to health care ontology, meets local and national needs, and is adequately harmonised across Europe (and beyond) to support the situation when the citizen moves.
- Developing suitable robust Models of Information System Custodianship, whereby ICT systems and the data they hold and process regarding social care and its integration with health care are provided by trusted parties accountable to, and monitored by, explicit and transparent standards.
- Developing models of Rights to Data Access, recognising and defining further the clear but distinct interests of the citizen as data subject, professionals involved in assessment and care delivery, named third parties, funding and monitoring organisations, and others to be defined; and also that 'data' will include *inter alia* contacts, activities, encounters, assessments, requests, goals and targets, mandates, and inter-agency liaison
- Developing clear and citizen-oriented Rules for Urgent Sharing of Information, accommodating in emergencies such as a change of personal condition (health or functioning), unexpected absence from home, and enquiries from police not least in cases of unusual or extreme behaviour.
- Identifying and codifying justifiable Needs for Access to Information other than immediate care delivery, with related authorisation and monitoring mechanisms – such reasons may include service delivery, quality and outcome monitoring, staff training and development, complaint investigation, and financial audit.
- Sponsoring Research and Development of Leading Edge ICT Innovation and Appropriate Application, including (but by no means restricted to)
 - controlled forms of information brokerage, cross-viewing, or record sharing between agencies and

providers, as well as by citizens and their supporters;

- the ethical, cultural, professional, legal and practical issues related to the joint management of health and social information and communication, and in particular to the generation and maintenance of a holistic synthesis of the health and social conditions of the subject of care;
- technology assisted scheduling, resource management, request handling, and negotiation;
- near real time delivery monitoring;
- integration of user messaging into scheduling systems;
- planning tools to enable citizens as well as formal carers to build packages of care within personal need, resource and policy constraints;
- assessment and decision support tools that assist both citizens and professionals when profiling needs or identifying risks;
- trusted data stores with representation of service type, providers, and availability in social and related care; new concepts of user-friendly intuitive devices utilising technologies such as touch screen and drag-and-drop; knowledge management services to help inform citizens' and carers' choices.
- Development of Education Programmes for citizens, carers, and professionals related to ICTs in Social Care and integrated health and social care support to health;

and to achieve all these goals, to **identify European Organisational Focal Points** for coordination of research, policy development, and practice support in Social Care Informatics and the integration of holistic care individualised to the citizen.

Meanwhile we **welcome**, as an important initial move, the concomitant proposal of participating officers of the European Federation for Medical Informatics to establish a Social Care Informatics and Individualised Health Working Group as one means of facilitating debate and development as a means to assisting progress.

On this 23rd Day of July 2010

[This Declaration was signed by all the Participants listed in Annex 1]



European Science Foundation
1 quai Lezay-Marnésia • BP 90015
67080 Strasbourg cedex • France
Tel: +33 (0)3 88 76 71 00
Fax: +33 (0)3 88 37 05 32
www.esf.org

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